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AUTHOR Horejsi, Charles R.; Berkley, Ann E.
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ABSTRACT

Reported are findings and recommendations from the University of Montana's Project on Community Resources and Deinstitutionalization which were derived from interviews with 86 service providers and nine social workers and from surveys of 61 retarded persons and their parents. It is explained that service providers most frequently identified the need for sheltered living arrangements to prevent institutionalization and depopulate the institutions, and that social workers felt community education and greater resources would increase the level of community acceptance. Summarized are parental views on such topics as satisfaction with their child's living arrangement, lack of community services, and confusion over service terminology. Described are recommendations for such service aspects as planning, program development and service coordination (including the need for program goals to conform to the developmental model and normalization principles); advocacy; placement procedures (including participation in decision making by residents and their parents or advocates); and residential services (including development of aggressive program for foster home recruitment). (CL)

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DEINSTITUTIONALIZATION AND THE DEVELOPMENT OF COMMUNITY BASED SERVICES FOR THE MENTALLY RETARDED YOUTH OF WESTERN MONTANA

Prepared by
CHARLES R. HOREJSI
and
ANN B. BERKLEY

Project on Community Resources and Deinstitutionalization
Department of Social Work
University of Montana
Missoula, Montana

EC 073 811

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Prepared by

Charles R. Horejsi

and

Ann B. Berkley

Project on Community Resources and Deinstitutionalization

Department of Social Work

University of Montana

Missoula, Montana

August, 1975

Project Staff

Morton L. Arkava, Ph.D.
Project Director

Fern L. Berryman
Secretary

Ann B. Berkley
Research Assistant

Charles R. Horejsi, D.S.W.
Principal Investigator

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Office of Child Development

U.S. Department of Health, Education, and Welfare

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PREFACE

The purpose of this report is to describe the activities which were part of the Project on Deinstitutionalization and Community Based Services for the Mentally Retarded, present a summary of findings and offer a set of recommendations. It is hoped that this report will be of use to parent groups, service providers, program planners and others in Montana who are concerned with the creation and expansion of community based services.

It should be noted that this report has been prepared for a nonprofessional audience. Professional jargon and technical concepts have been avoided wherever possible. It is also important to note that this report is one of two prepared by the Project. A second report, Deinstitutionalization and the Development of Community Based Services for the Mentally Retarded: An Overview of Concepts and Issues, reviews problems and issues related to deinstitutionalization and the creation of community based services. A reading of that report will aid in the understanding of recommendations offered here.

INTRODUCTION

WESTERN MONTANA

The Project on Deinstitutionalization and Community Based Services for Mentally Retarded Youth focused on Montana's Region V, an essentially rural, mountainous seven county area of Western Montana. The counties of Missoula, Flathead, Lake, Ravalli, Lincoln, Sanders and Mineral make up this Region. It is about 242 miles in length and about 100 miles in width. In area it consists of 19,339 square miles, an area over one-half the size of Indiana or about the size of New Jersey, Connecticut, and Massachusetts combined. In land area Region V is the smallest of five regions in Montana. According to the 1970 census, 154,691 persons lived in Region V. This was 22.3% of Montana's population of 694,409. The Region's density is eight persons per square mile.

Forest products, agriculture and tourism are central to the Region's economy. The Region's largest city, Missoula, has a population of about 35,000 and serves as a major trade, medical and educational center. Kalispell, the second largest city in the Region, has a population of about 12,000 and is located 115 miles north of Missoula. The third largest city, Libby, has a population of 3,286 and is 190 miles from Missoula and 89 miles from Kalispell.

PURPOSE OF PROJECT

The four objectives of this research effort were to (1) increase knowledge of the factors, process and procedures affecting the release of

mentally retarded youths from the Boulder River School and Hospital; (2) increase knowledge of the social, educational, financial and health needs of deinstitutionalized youths and their families; (3) prepare recommendations and formulate feasible approaches to the development and delivery of needed mental retardation services in Western Montana; and (4) communicate findings and recommendations to relevant organizations and decision-makers responsible for the planning and development of mental retardation services and programs. In order to reach these four basic objectives, data were gathered from a variety of sources (parents of retarded youths, retarded persons, providers of service, Boulder River School and Hospital staff, State level planners and administrators, etc.) and in a number of ways (indepth interviews, participant observation, mailed questionnaires, etc.).

The overall goal of the Project was to develop practical information and feasible recommendations which would facilitate deinstitutionalization and the development of the community based services in a rural area. Since the Project staff was committed to the notion that research of this type should be utilized rather than stored in a library, great emphasis was placed on making the research process useful and useable to service providers, parent groups, program planners, legislators, etc. This commitment influenced decisions on exactly what was studied and the methodology used.

PROJECT CONTEXT

Officially, this project began September 1, 1974, and ended August 31, 1975. It was conducted during a year when significant and far reaching legislative decisions were made concerning deinstitutionalization and

services for the mentally retarded in Montana. The Project was clearly affected by these decisions and, to some degree, probably affected the decisions that were made. A brief overview of 1974 and 1975 events are necessary to understand many project activities.

The initial project proposal was born out of a concern over the lack of community based services for retarded persons in Western Montana. Numerous parents and providers of service shared this concern and endorsed the proposal. The proposal was written in March, 1974, while Montana's institution for the mentally retarded, the Boulder River School and Hospital (BRS&H), was in the turmoil of an employee strike. The BRS&H is Montana's only full range institution for the care, treatment and training of mentally retarded persons. Boulder, the institution's host community, has a population of 1,300 and is located 30 miles from Helena and 37 miles from Butte. The BRS&H is a considerable distance from Region V communities. It is 141 miles from Missoula, 256 miles from Kalispell and 331 miles from Libby.

Like many state institutions, the care, treatment and training provided by BRS&H has been inadequate for many years. The March, 1974, strike called this fact to the public's attention. Basically, the strike was caused by a failure of the 1974 Montana Legislature to adequately fund BRS&H and other state institutions. The National Guard was mobilized to help staff BRS&H during the strike. News coverage and numerous reports provided by the guardsmen served to further inform the public of the deplorable conditions at the BRS&H. When the strike finally ended, the stage was set for the 1975 Legislative session. State institutions were to be the 'number one' priority and issue.

Community based alternatives to institutional care have been slow to develop in Montana. A lack of funding nas been a major obstacle. It is interesting to note that House Bill 412 (Developmental Disabilities Services and Facilities Act) which provided for the establishment of community based services was passed but not funded by the 1974 Legislature.

In July, 1974, several months after the strike, a severe staff shortage forced BRS&H to place about 100 residents into "emergency placements," mostly nursing homes. This reduced the BRS&H resident population to slightly more than 400. The need for such emergency placements was an additional symptom of the many problems which plagued BRS&H. High staff turnover, lack of trained personnel, public outrage over several accidental deaths, and inadequate physical facilities were some of the more tangible problems at the institution.

In September, 1974, the same month this Project got underway, the Governor's Office, key service providers, parent groups and interested citizens began considering proposals and options which would address the BRS&H crisis. In preparation for the 1975 Legislative session, public meetings were held throughout the state. 'Grass roots' ideas and support were invited and obtained. Parents and parent groups voiced strong support for the development of community based alternatives to institutional care. Thus, funding for the Developmental Disabilities Services and Facilities Act of 1974 became a prime goal.

On November 8, 1974, the United States Justice Department filed a civil action against the BRS&H on behalf of residents and potential residents. Essentially, this was a right to treatment suit. At the time of this writing, further action on this right to treatment suit is pending.

The 1975 Legislative session began in January. At this time Montana found itself in a peculiar dilemma. BRS&H was clearly inadequate and faced a law suit. Massive amounts of money would be needed to upgrade the institution. Budget requests placed future institutional care cost at about $25,000 per resident, per year. Money would not, however, solve the inherent problems of institutional-type care. Depopulation seemed essential and had been recommended in a September 1974 Staff Report to the Joint Interim Subcommittee on Finance and Claims. The report, Community Alternatives to Institutionalization, stated, "If proper treatment is to be provided to the residents at BRS&H, the population must be reduced as quickly as possible to 252--the number of Medicaid certifiable beds now available." The dilemma, of course, was that the community based services necessary to reduce the BRS&H were lacking. Thus, the Legislature was being asked to invest large amounts of money in both the institution and community based services. This was a situation which many legislators found difficult to understand. Many favored funding one or the other but not both. Lobbying by parents, providers and the retarded themselves did, however, convince the Legislature of the need for community based services.

In addition to providing a substantial funding increase to BRS&H, the 1975 Legislature passed H.B. 353, an ammended version of the 1974's H.B. 412. For the next biennium, over five million state dollars were provided for the development of community based services for the developmentally disabled. When matched with Title XX monies, substantial funding will be available.

A rather unique feature of H.B. 353 is the creation of five Regional Councils throughout Montana which will permit consumers, parents and local

citizens to plan and make decisions on needed services in their area. State purchase of service contracts will be used to fund local programs approved by Regional Councils. Thus, Montana citizens and communities now have an opportunity to develop services which will assist in the prevention of institutionalization and permit over 200 BRS&H residents to return to the community. The BRS&H population is to be cut in half by 1977.

PROJECT STAFF

Paid Project staff consisted of a Principal Investigator and a Research Assistant, both full-time, and a three-fourth's time Secretary. The unpaid Project Director donated the time necessary to handle various administrative aspects of the Project.

RESEARCH DESIGN AND METHOD

The term 'research design' refers to the logical strategy of a study. The overall strategy of this project can best be described as a diagnostic or descriptive research design utilizing comparison groups and coupled with features of community need assessment and action research. According to Kahn (1960), the diagnostic-descriptive design is commonly used when the purpose of the research is to "...assess characteristics of phenomenon or to describe relationships between variables." (p. 58) It is frequently used when the research is related to administrative and professional questions and is of particular "...value for planning, policy selection and program implementation." (Kahn, 1960, p. 53)

The term 'action research' refers to a process-oriented approach which

is intended to increase the chances that research findings and recommendations will be understood, accepted and implemented by decision-makers and program planners. Carter (1952) formulated several principles of action research. Among these are the following:

> The problem(s) for research should stem from a recognized need rather than [an] hypothesis generated from the personal interests of the research specialist.
>
> For maximum effectiveness, those who are expected to implement the recommendations should participate in the study process.
>
> Action research in community planning implies teamwork among researchers, other professionals, technicians and lay citizenry. (pp. 23-28)

Not infrequently, research efforts yield a written report which 'sits on a shelf' and has little or no impact on decision makers. Adherence to principles of action oriented research is intended to facilitate research utilization.

For purposes of explanation, it is helpful to separate two broad sources of data which yielded the research findings and provided the basis for recommendations offered in this report. One category includes specific case by case information gathered on four groups of retarded persons, their parents and their service needs. As used here, this category will be termed client/family data. The second category consists of information secured from service providers, program administrators, BRS&H staff, decision makers, etc. whose perspectives and concerns were community-wide, regional and sometimes state-wide. Data gathered from these persons focused, for example, on the retarded and services in general, rather than on case data. In this report, this second category will be termed provider/decision-maker data.

PROVIDER/DECISION-MAKER DATA

Throughout this year-long research project, information was gathered from and exchanged with providers, BRS&H staff, representatives of Association for Retarded Citizen Chapters, state program planners, selected legislators, etc. There was no clear beginning or end to this information gathering process. Clearly it was an ongoing, two-way exchange of information.

During the early months of the Project, the researchers visited numerous programs and providers of service in Western Montana. In addition, meetings such as those of the Association for Retarded Citizens, Council on Exceptional Children and Developmental Disabilities Regional Council were attended. The researchers met or acquired the names of many professionals and citizens having a special interest in services for the retarded. A type of reputational technique was used to identify key persons within this service 'community.' As the researchers talked with individuals or groups they asked for the names of other persons who should be contacted. Persons named most often were assumed to be those who were most influential and knowledgeable within the service system of Western Montana. Special efforts, both formal and informal, were made to secure their ideas and opinions.

Between December, 1974, and February, 1975, an attempt was made to secure more systematic information from these providers and program administrators. A questionnaire was formulated which asked numerous questions about needed services, priorities, needed changes in the existing service system and views on deinstitutionalization. For the most part, responses were secured by mail but in some cases personal interviews were used to secure this data. Information was gathered from a total of 86 providers

and/or administrators.

The two researchers scheduled and/or attended nearly 200 separate meetings with individuals or groups related, directly or indirectly, to the planning and provision of services for the retarded or to some aspect of deinstitutionalization. Several of these meetings were with State Legislators or other elected officials such as County Commissioners. Such meetings yielded both hard and soft data.

In keeping with the Project's action orientation, the researchers were deeply involved in issues before the 1975 Montana Legislature and worked closely with Representative Ann Mary Dussault, a Missoula Legislator, who introduced H.B. 353 which proposed substantial changes in the Montana Developmental Disabilities Services and Facilities Act of 1974. In April, 1975, House Bill 353 was passed and funded, thus providing over five million state dollars for community based services and deinstitutionalization. Involvement in this legislative process provided the researchers with a unique perspective on the economic and political aspects of deinstitutionalization.

During the year the project staff prepared numerous brief reports and statements designed to be of practical assistance to providers, parent groups and decision makers in the Region. Some of these were the following: 'Services for the Mentally Retarded: Some Facts and Comments;' 'Information Update on H.B. 353;' 'D.D. Service Terminology;' 'Follow Along Services;' 'A Summary of Opinions Offered by D.D. Service Providers in Western Montana;' 'Prevalence of Mental Retardation;' 'D.D. Related Services in County Departments of Public Welfare;' 'Sources of Information on Mental Retardation;' etc.

During the year the researchers made several presentations at public meetings and conferences (e.g., the Governor's Blue Ribbon Commission on Mental Health, Montana League for Nursing, Ravalli County Grange). The researchers also assisted in the preparation of several news releases and feature articles on developmental disabilities and the need for deinstitutionalization.

An additional type of activity generated by this action oriented project was an out-of-state program visit. Visits to mental retardation programs in other communities and states can be a fruitful source of new program and planning ideas and a stimulus to program development in ones own area. In December, 1974, thirteen people from Western Montana made such a trip to Spokane, Washington. It was sponsored by the Project. The purpose of the trip was to visit and observe a variety of services for the mentally retarded and thereby gather information which would be helpful in the planning and development of similar services in Montana. Among those making the trip were a regional director of mental health services, a group home supervisor, the administrator of a region-wide children's diagnostic center, a regional supervisor for rehabilitative services, the president of an A.R.C. Chapter, a public school administrator, a nursing home administrator, the directors of two sheltered workshop programs, a social worker from BRS&H, an agency board member and the two researchers who arranged the trip. The participants were drawn from six Montana communities. Distances between these communities ranged from 50 to 332 miles.

Individual program visits were selected and scheduled by staff at the Spokane Office of Developmental Disabilities (O.D.D.). Two O.D.D. staff members accompanied the participants, sharing ideas and answering many

questions. A trip of this sort provided the participants with: (1) an opportunity to meet with knowledgeable persons from another state and observe programs operating within a different administrative and social environment and (2) an opportunity to meet informally with persons from ones own state and learn of each other's programs, plans and concerns. Needless to say, the logistics of planning a two-day trip required many hours and many telephone calls and letters. The possibility of such a trip was, however, received with enthusiasm by those invited to participate. A willingness to be on the road at 7 a.m. of the first day, crossing snow covered mountain passes one week before Christmas, not returning until 10 p.m. on the second day (39 hours later) and riding in a mini bus for 450 miles is evidence for the conclusion that the participants were eager for the learning experience the trip offered.

In August, 1975, the Project and the Montana Association for Retarded Citizens jointly sponsored a two-day workshop on Program Analysis of Service Systems and Normalization presented by Linda Glenn, Executive Director of the Eastern Nebraska Community Office of Retardation. The workshop was attended by parents, providers of services and program planners from across Montana. It was designed to be of use to persons directly involved in the development of community based services under the provision of H.B. 353.

Throughout the year the Project staff gathered information from other states (e.g., Nebraska, California, Connecticut, North Dakota, etc.). Whenever possible this information was passed on to parent groups, providers and state level planners.

CLIENT/FAMILY DATA

In order to secure an understanding of the factors and issues associated with institutionalization, the prevention of institutionalization and the placement of the institutionalized retarded into community programs, data were gathered on four groups of mentally retarded youth who were less than 20 years of age on September 1, 1974, and related to Region V (Western Montana) in one of the following ways:

GROUP I: BRS&H residents, as of September 1, 1974 who were from Region V. (abbreviation used--BRS&H)

GROUP II: Former BRS&H residents who were from Region V and who were placed in the Region after September 1, 1972. (abbreviation used--P.O.)

GROUP III: Retarded youth from Region V who were evaluated at BRS&H after September 1, 1972 but not admitted to the Institution. (abbreviation used--EVAL)

GROUP IV: Selected retarded youth living in Region V on September 1, 1974 who had never received service from the BRS&H. (abbreviation used--NEV)

A major source of client and family data were indepth interviews with the parents of these retarded youth. These semi-structured interviews generally lasted from one and one-half to five hours. Supplemental data were drawn from BRS&H records and/or obtained directly from BRS&H staff. Where possible, data were also gathered directly from retarded persons. For clients within Group IV, supplemental data were secured from the records and staff of the Western Montana Child Development Center, a regional diagnostic center.

In October, 1974, an examination of BRS&H statistical data identified 54 persons who met the criteria of Groups I, II and III. At that time only case numbers and selected descriptive data on these 54 individuals

were available to the researchers. The release of more detailed information including the names and addresses of parents was contingent upon a formal release of information procedure. Securing the names and addresses of the parents or guardians was a necessary prerequisite for arranging research interviews and securing data directly from BRS&H records. A letter signed by the Acting Superintendent of BRS&H was sent to 51 of the parents or guardians. (Because three of the former BRS&H residents had died no attempt was made to contact their parents.) It briefly explained the study and requested the return of a signed authorization for the release of information. Several weeks later a second letter was sent to those who did not respond to the first one. Altogether, releases were obtained from 38 of the 51 parents or guardians. One set of parents could not be located; the others presumably chose not to provide a release of information.

Once the releases had been secured the researchers attempted to arrange interviews with the parents or parental surrogates. Of the 38 families, interviews were obtained with 36. Two could not be located or decided not to participate subsequent to signing the release.

Most of the parents of the mentally retarded youth comprising Group IV were initially contacted by Child Development Center (CDC) staff and asked if they would participate in the study. If they agreed, a signed release of information was secured. This permitted the researchers to contact the family and have access to CDC records. A total of 19 parent interviews were secured in this manner. An additional six parent interviews were arranged through Association for Retarded Citizens (ARC) chapters in the Region. A deliberate attempt was made to secure interviews with parents

from each of the seven counties in the Region.

It is important to note that the release of information procedures used to protect the confidentiality of records and freedom of choice constricted the study population. Moreover, factors of feasibility and ordinary administrative constraints within the BRS&H did not permit adherence to sampling techniques which would have resulted in a population known to be representative. In other words, data were not obtained on those who, for one reason or another, elected not to participate in this study. However, the fact that 36 of 51 possible sets of parents of youths in Groups I, II, & III chose to participate indicates that a cross-section may have been reached.

The same constraints affected families in Group IV. The C.D.C. staff made deliberate efforts to secure what they considered to be a cross-section of Western Montana parents who had not sought service from BRS&H for their retarded child. While it is reasonable to assume that the families selected by this method were fairly typical, it cannot be said that they were truly representative in the statistical sense. It must also be noted that all of the families who participated in this study were ones who had sought service from the BRS&H, CDC or were affiliated with the ARC. It is quite possible that some families have not utilized any of these services or programs. Such families were untouched by this study.

Theoretically speaking, hundreds and even thousands of bits of information could have been gathered on the retarded youths and their families. Since it was not feasible to gather all possible data, choices had to be made on what data would be sought. Utilization criteria guided these choices.

Prior to formulating interview schedules and questionnaires, numerous parents and providers were interviewed in an attempt to identify the types of data which could be utilized to plan and improve community based services for the retarded and further successful deinstitutionalization in Western Montana. In keeping with the action-orientation of this project, their suggestions and requests for information had more to do with the selection of a study focus than did the researcher's interests and curiosities.

REPORTED DATA AND RECOMMENDATIONS

Rather than attempt to report voluminous detail which is often difficult to comprehend, this report focuses on those highlights and generalizations which can be utilized in program development and planning for deinstitutionalization. In other words this report focuses on findings which can be translated into action. Special effort was devoted to the task of preparing a report which utilized a minimum of professional jargon and one which would be understandable to the nonprofessional reader.

Wherever possible recommendations or suggestions have been offered by the researchers. A list of recommendations appear as a final section of this report. (see pages 73-95)

AN OVERVIEW OF BRS&H RESIDENTS AND SERVICE NEEDS

SELECTED CHARACTERISTICS

As of April 1, 1975, 399 persons resided at the BRS&H. This number did not include the approximately 90 individuals who remained on "emergency placements," many of whom were in nursing homes throughout the state. Of the 399 at BRS&H, 239 were males and 160 were females. Age distribution and level of retardation is shown below.

AGE GROUPS	LEVELS OF RETARDATION						
	UNKNOWN	NORMAL	MILD	MODERATE	SEVERE	PROFOUND	TOTAL
0 - 5	3	0	0	0	0	7	10
6 - 12	0	0	2	2	5	41	50
13 - 17	0	0	5	5	16	51	77
18 - 21	0	0	5	23	38	63	129
22 - 25	0	0	2	1	2	14	19
26 +	0	2	6	20	24	62	114
TOTAL	3	2	20	51	85	238	399

It is noteworthy that 238 (59.6%) were profoundly retarded and another 85 (21.3%) were severely retarded. In other words, 81% were either profoundly or severely retarded. Less than 20% function at the mild and moderate range.

The Report to the Legislators of the State of Montana on the Boulder River School and Hospital (1974) states that 22% of the BRS&H residents are

blind or visually impaired, 13% are deaf or hearing impaired, 7.4% have both vision and hearing defects, 32% have cerebral palsy, 34% have epilepsy and 18% have both cerebral palsy and epilepsy. The report further indicates that almost 50% are not toilet trained, more than one-half need help bathing and over one-third need help eating. About 20% are unable to walk and one-third were non verbal. Needless to say, these data point to some of the problems involved in deinstitutionalization for the mentally retarded.

Despite the many needs of the residents, BRS&H has not been successful in providing services. According to the report cited above, the average number of supportive services available to each resident was 1.2. Support services are those beyond custodial care or those not necessary for physical survival (e.g., education, recreation, physical therapy, training, counseling, etc.). Sixty-six percent of the residents received none or only one supportive service.

PROJECTED LIVING ARRANGEMENTS

In September, 1974, the total BRS&H caseload was 527. Included in this total were approximately 400 persons living at the institution and about 100 who had been placed in community health care facilities (mostly nursing homes). It was in July, 1974, that 110 residents left the institution on "emergency placements" because of a critical staff shortage. By December, 1974, 91 of the 110 remained in community health care facilities whereas 16 had returned to BRS&H, one had been discharged, one had been placed in his parent's home and one had died.

In September, 1974, BRS&H staff reviewed the entire caseload and

formulated a 'projected living arrangement' for each client. These projections were one method of determining the types of living arrangements which would have to exist in order to effect total depopulation. The projections were based on the staff's knowledge of client functioning and need but without regard to the actual availability of appropriate community based services to meet these needs. The projected living arrangements are shown below.

Group Home	256
Group Home (Handicapped)	14
Foster Home	80
Foster Home (Handicapped)	42
Foster Home or Group Home	52
Foster Home or Group Home (Handicapped)	21
Skilled Nursing	8
Skilled Nursing (Handicapped)	29
Treatment Center	17
Treatment Center (Handicapped)	1
Independent/semi-independent	7
TOTAL BRS&H CASELOAD (September, 1974)	527

It is important to note that 465 of the 527 were in need of either a foster home or group home. Because of physical handicaps, 77 of the 465 needed homes with special structural accomodations (e.g., wide doors for wheel chairs, special toilet facilities, etc.). Of the total September, 1974, BRS&H caseload, 156 had significant physical handicaps.

SERVICES NEEDED BY A GROUP OF YOUNG BRS&H RESIDENTS

In April, 1975, Project staff and BRS&H personnel reviewed the service needs of 26 BRS&H residents from Western Montana who met age criteria for inclusion in the study population. Thus, all were less than 20 years of age on September 1, 1974. Older residents were not included in this review.

The parents of 15 of the 26 residents had been interviewed by the Project staff prior to the 'case by case' review at BRS&H. These 15 made up Group I of the study population. Releases of information had not been secured on the other 11. Thus, BRS&H discussed their service needs but did not reveal identifying data to the researchers.

Of the 26 residents, three were mildly retarded, two were moderately retarded, three were severely retarded and eighteen or over three-fourths were profoundly retarded. Fourteen were females, twelve were males. Essentially, the BRS&H staff attempted to identify those services which would be needed by each resident within one year after placement out of the institution. Thus, the services identified by this process were ones which would need to exist in Western Montana if these residents were to be placed in the community and appropriately served by community based programs. It is important to emphasize that many of the needed services identified by this process were neither available at BRS&H nor in Western Montana. In other words, the process simply identified services needed by each resident, irregardless of whether the resident could receive this service at BRS&H or whether the service was currently available in the community.

Obviously, all of the 26 would need more than a single service. The totals shown below reveal the number of persons needing each particular service. Some projections invisioned progression from one type of service to another even within one year after community placement. The service classification used in this process was one utilized at BRS&H.

SERVICES NEEDED BY 26 BRS&H RESIDENTS WITHIN ONE YEAR AFTER PLACEMENT

EVALUATION SERVICES:

Physical Eval.....12
Medical Eval. (annual).....25
Genetic Eval..... 0
Other Medical Eval..... 2
Dental Eval.....25
Opthamological Eval.....18
Psychological Eval.....23
Psychiatric Eval..... 1
Vocational Eval.....11
Educational Eval.....24
Behavior Modification Eval.....26
Deaf-Blind Eval..... 2
Recreation Eval.....26
Speech Eval.....20
Hearing Eval.....15
Social Eval.....24
Economic Eval.....15
Legal Eval..... 8
Environmental/Cultural Eval..... 8

DIAGNOSTIC SERVICES:

Psychological Diagnosis..... 1
Social Diagnosis..... 7
Medical Diagnosis..... 4

DAY CARE SERVICES:.....24

EDUCATION SERVICES:

Pre academic..... 2
Deaf-blind..... 2
Regular education..... 0
Special education.....17
Pre school education..... 1
Deaf education..... 1

SHELTERED EMPLOYMENT:..... 1

Evaluation..... 5
Work adjustment..... 5
Occupational skill therapy..... 6

RECREATION SERVICES:.....26

FOOD, SHELTER, CLOTHING:.....26

TREATMENT/TRAINING SERVICES:

Infant stimulation..... 0
Surgical..... 0
Dental..... 6
Psychiatric..... 0
Psychological..... 6
Dietary control..... 1
Chemotherapy (medication)..... 4
Physical therapy..... 8
Occupational therapy..... 8
Behavior Modification.....22
Toilet training.....14
Eating training.....11
Dressing training.....16
Compliance training..... 2
Speech & Language Development.....22
Personal Hygiene training.....20
Social Skills training.....25
Pre Vocational training.....13
Elimination of Maladaptive/
Inappropriate Behavior.....18
Speech therapy.....14
Counseling or other services..... 9
Genetic Counseling..... 0
Other Counseling..... 1
Appliance services..... 4
Other training.....10

COUNSELING SERVICES:..... 1

Family counseling.....13
Vocational counseling..... 5
Religious counseling..... 0
Counseling related to undesirable
social behavior..... 1

INFORMATION & REFERRAL:.....12

FOLLOW ALONG SERVICES:.....26

PROTECTIVE & SOCIAL-LEGAL SERVICES:

Protective (social).....25
Protective (legal).....26

TRANSPORTATION:.....25

FINANCIAL SUPPORT:.....26

Many of the services identified above are ones needed by the severely and profoundly retarded. At the time of this writing, few Montana communities have appropriate services for such persons. It is important to note that all or nearly all of the 26 individuals need certain services such as protective services, follow along, financial support, recreation, regular medical and dental care, etc. Also, most individuals need behavior modification services for the elimination of maladaptive or institutional behavior.

Projected living arrangements had been formulated for 32 of the persons who were part of the study population, the 26 BRS&H residents plus six others who had been placed out of BRS&H but were still part of the official BRS&H caseload. These projections indicated a great need for foster homes. The available information made it possible to compare the actual living arrangement with the projected living arrangement. This yielded one measure of appropriateness in placement. These comparisons are shown below.

	PROJECTED LIVING ARRANGEMENT	ACTUAL LIVING ARRANGEMENT	
		IN BRS&H	IN NURSING HOME
Group Home	1	1	0
Group Home (Handicapped)	1	1	0
Foster Home	14	14	0
Foster Home (Handicapped)	4	2	2
Foster Home or Group Home	6	5	1
Skilled Nursing	4	1	3
Natural Home or Foster Home	1	1	0
Treatment Center	1	1	0
TOTAL	32	26	6

This comparison shows that only the three clients in skilled nursing facilities were in an appropriate living arrangement. All of the others are in an arrangement which differed from the projected living arrangement based on client needs. Stated differently, 29 of the 32 were in inappropriate living arrangements.

These data and comparisons indicate that many BRS&H residents could live and function outside the institution if community based alternatives were available. Group homes and foster homes are among the most needed living arrangements. These data also point to an overuse and inappropriate use of nursing homes as alternatives to institutional care.

FINDINGS DERIVED FROM INTERVIEWS WITH PROVIDERS AND OTHER SOURCES OF DATA ON EXISTING AND NEEDED SERVICES

OPINIONS OF EIGHTY-SIX PROVIDERS

During the early months of the project, the staff visited numerous programs and providers of service in Western Montana. In addition, meetings such as those of the Association for Retarded Citizens, Council on Exceptional Children and the D.D. Regional Council were attended. As a result of these activities, the project staff met or acquired the names of many professionals having a special interest in services for the mentally retarded. Informal discussions and unstructured interviews with many of these providers were used to obtain information on programs, plans and problems in the Region.

Between December, 1974, and February, 1975, an attempt was made to secure more systematic information from providers and program administrators. A questionnaire was formulated which asked numerous questions about needed services, priorities, and needed changes in the existing service delivery system. For the most part responses to the questionnaire were secured by mail but in some cases answers were obtained by way of personal interviews.

Data were gathered from a total of 86 providers and/or program administrators. The return rate on mailed questionnaires was about 60%. This fairly high return rate was undoubtedly due to the fact that the Project staff was known to many of those receiving the questionnaire. Those responding were not part of a scientifically drawn sample. Rather, the questionnaire was used to gather information from persons known to be providing D.D.-related services or known to have a professional interest in such services.

Characteristics of Providers

Of the 86 providers offering information and opinions on mental retardation services and needs, slightly more than one-half were women. Most were married. Ages ranged from 23 to 65. Their mean age was 39. About one-half held advanced degrees, mostly at the master's level. Eleven had doctorates and four had less than a college education. Their positions or relationship to retardation services are summarized below.

Special Education Teachers and/or Special Ed. Administrators	18
County Social Workers and/or Public Social Service Administrators	13
County Public Health Nurses	11
County School Superintendents or School Administrators	8
Nursing Home Operators	7
Psychologists (Mental Health Center and Private Practice)	5
School Psychologists	3
Physicians (Public Health and Private Practice)	3
Social Security Workers and Administrators	3
Vocational Rehabilitation Counselors or Administrators	3
Speech Pathologists	2
Psychiatric Social Workers (Mental Health Center and Private Practice)	2
Group Home Supervisors	2
Sheltered Workshop or Work Activity Administrators	2
Physical Therapist	1
Other Program Administrators or Providers	3
	86

As might be expected, most of the providers were from the more populated counties. The number of respondents from each of the seven counties was as follows: Missoula, 38; Flathead, 17; Lincoln, 12; Lake, 8; Ravalli, 6; Sanders, 4 and Mineral, 1.

Service Coordination and Integration

The providers were asked several questions which focused on the coordination and integration of D.D.-related programs and services. More specifically, they were asked if problems existed in this area and if so, how

better coordination and integration could be achieved.

Sixty-five providers answered these questions. Of these, 52 --a majority-- thought that there was a problem. Only seven did not believe that a problem existed and eight were unsure. It is interesting to note that four of the seven who reported no problem were from the smaller counties. One respondent explained her answer by saying that a lack of coordination was not a problem in her county because, unfortunately, there were no services to be coordinated.

A variety of suggestions were offered as a means of increasing coordination and integration. One, however, was mentioned more than any other. Forty respondents suggested that a single agency should be responsible for case managements and follow along services. This suggested solution is consistent with the often repeated 1962 President's Panel on Mental Retardation recommendation that:

> ...services be so organized as to provide a central or fixed point for the guidance, assistance, and protection of retarded persons if and when needed, and to assure a sufficient array or continuum of services to meet different types of needs. (pp. 14-15)

Nineteen providers suggested the creation of an inter-agency coordinating council or a similar mechanism which would bring agency representatives and workers together for the purpose of increasing communication and coordination. Such a council would meet on a regular basis to discuss common problems, share plans and keep abreast of changes in agency programs.

Five believed that an information and referral service was needed. It would serve to guide the retarded and/or their parents to the proper program. In some respects this suggestion is similar to the one advocating a single agency responsible for follow along and case management.

Other suggestions mentioned the need for technical assistance and consultation to new and developing programs and the need for role clarification among agency workers. Apparently these suggestions reflect the belief that well designed programs and a clarity of agency purpose facilitates coordination and integration.

Prevention of Institutionalization

The providers were asked to identify the three types of service which would be of greatest value in preventing the institutional placement of mentally retarded persons. The 12 services identified most often were as follows.

Service	No. of times identified
1) Sheltered Living Arrangements (Foster Homes, Group Homes, etc.)	41
2) Training and Education for Retarded	37
3) Sheltered Employment (Workshops, Work Activity, Regular Jobs, etc.)	32
4) Counseling for Retarded and/or Parents	24
5) Respite Care	14
6) Evaluation and Diagnosis	12
7) Treatment Services (Medical, Dental, Behavior Modification, Speech Therapy, etc.)	11
8) 24-hour Supervisory Care (Skilled Nursing Home, Residential Care, etc.)	10
9) Follow Along Service	8
10) Day Care	8
11) Transportation	8
12) Information and Referral	7

In addition to the services listed above, financial assistance, recreation, personal care services and protective services were also mentioned. Sheltered

living arrangements, training and education and sheltered employment were viewed as key services. It is noteworthy that transportation was seen as a greater need in the sparsely populated counties than in those which contained larger cities. One county social worker underscored the impact of distance on the delivery of service by citing the fact that her county had one-half the land area of Massachusetts.

Depopulation of Institution

Another question asked the providers to identify the three types of service which would be of greatest value in returning the institutionalized retarded to the community. The 12 services identified most often are presented below.

Service	No. of times identified
1) Sheltered Living Arrangement	46
2) Sheltered Employment and Work Activity	36
3) Training and Education	27
4) Recreation	19
5) 24-hr. Supervisory Care	15
6) Respite Care	11
7) Counseling	9
8) Transportation	9
9) Treatment Services	9
10) Follow Along	8
11) Day Care	8
12) Community Education	7

Other services mentioned included information and referral, financial assistance, personal care and evaluation. Clearly, sheltered living arrangements, sheltered employment, work activity, training, and education are

among the most needed services. It is interesting to note that community or public education ranked ninth in the above list but was mentioned only once among the approaches needed to prevent institutionalization. This may reflect the belief that the formerly institutionalized retarded encounter more discrimination than those in the community. Also, evaluation and diagnostic services are apparently viewed as being less important in facilitating the return of persons from the institution than in the prevention of institutionalization.

Community Acceptance of the Deinstitutionalized Persons

Sixty-six of the providers answered a question which asked how most people in their area would react to the placement of persons from the Boulder River School and Hospital into their community and neighborhood. Their responses are shown below.

Placements would be encouraged	7
Placements would be approved but not encouraged	28
Placements would be tolerated but neither approved nor encouraged	30
Placements would not be tolerated	1

These opinions seem to reflect the belief that persons placed out of Boulder would receive a rather 'luke warm' reception in the community.

While it is difficult to generalize on the basis of a relatively small number of non random responses, the data did not point to a relationship between level of acceptance and community size. In other words, opinions offered by providers in small communities were similar to those of providers from the larger communities.

The providers were also asked for their own reaction to the placement

of retarded persons from Boulder into their community and neighborhood. Their views were as follows:

Placements would be encouraged.....49
Placements would be approved but not encouraged.....14
Placements would be tolerated but neither approved nor encouraged. 1
Placements would not be tolerated..... 0

It is interesting to note that the providers rated themselves as being more tolerant than other people in their community. In view of the fact that the providers have more experience with and knowledge of the retarded, their self assessment is probably accurate. Myths and fears of the retarded are more likely to exist among persons with little or no exposure to the retarded.

COUNTY SOCIAL SERVICES

Given Montana's current governmental structure, the Department of Institutions and the Department of Social and Rehabilitative Services (S.R.S.) play key roles in the planning and implementation of institutional depopulation. The two groups of service providers most directly involved in the actual placement of persons out of the institution are social service personnel at BRS&H and S.R.S. social service staff at the county level. County social workers carry much of the responsibility for making placements (e.g., foster homes, nursing homes, etc.).

In an attempt to better understand some of the practical issues in placement, Project staff interviewed nine county social workers in January, 1975. Two were from Missoula County and two were from Flathead County. One social worker was interviewed from each of the other five counties in the Region.

Number of Clients Served

The results of the survey indicated that during December, 1974, 260 developmentally disabled (D.D.) clients were receiving services from the seven county departments of public welfare in Western Montana. Of the 260, 33 were under the age of 18 and 227 were over the age of 18. Living arrangements for these two age groups is shown below.

Age Group	LIVING ARRANGEMENT							
	Foster Home	Parent's or Relative's Home	Group Home	Independent Living Arrangement	Intermediate Care	Skilled Nursing Care	Other	Total
Under Age 18	10	19	0	0	0	2	2	33
18 and Over	6	75	18	20	62	42	4	227
TOTAL	16	94	18	20	62	44	6	260

Persons not Receiving Public Social Services

The social workers were asked if they knew of other developmentally disabled persons in their county who for one reason or another (eligibility, having not requested service, etc.) were not receiving service from the County Department of Welfare. A total of 208, both adults and children, were known to these nine workers.

Caseload and Workload

It is difficult to accurately assess or describe social service caseloads or work loads in public welfare agencies. Simply counting the number of persons or families served per month is deceptive in that such a count does not describe the amount of time actually invested in the provision of service. Moreover there is no such thing as an "average client." Different clients require different types or different combinations of services. The provision of some services or dealing with a crisis situation may absorb many hours of the social worker's time. Other equally important services may demand little time.

Only two of the nine workers devoted full time to a caseload of developmentally disabled (D.D.) clients. All others had child welfare, Aid to Families with Dependent Children, and other social service responsibilities in addition to their D.D. related service activity.

The interviews revealed that 16 county social workers had D.D. clients in their caseload. Eleven devoted less than one-fourth time to D.D. related services and one worked one-fourth time on D.D. cases. Two devoted one-half time and two workers in Missoula County devoted full time to a D.D. caseload. The total time available to D.D. clients added up to a 'full time equivalent' (FTE) of 4.3. In other words, the total amount of worker time devoted to D.D. clients was equivalent to a little over four full-time social workers. Using a FTE of 4.3 and total regional D.D. caseload of 260 clients, the average D.D. caseload for December, 1974, was calculated to be 59.8.

As previously indicated, only two of the 16 workers having D.D. service-related responsibilities had completely D.D. client caseloads. All others

had additional responsibilities for non-D.D. clients. Total caseloads (all clients) for these workers ranged from 50 to 115, the average being about 77.

Needed Training

Five workers voiced a need for greater knowledge and skill in the area of community organization and planning (i.e., program development, organizing support for programs, planning, etc.). An equal number wanted additional training in counseling and casework with the D.D. client and his/her family. Two expressed a need to know more about epilepsy, cerebral palsy and autism (i.e., the other D.D. conditions). One wanted a better knowledge of legal issues related to the D.D. client; one wanted a better understanding of the current D.D. programs and policy. One worker complained that she simply didn't have time to leave the county for additional training.

Concerns Expressed by the Workers

Five of the nine workers expressed concern over the fact that D.D. persons were not accepted in communities. They thought some type of "community education" was needed in order to increase the level of acceptance. Four workers expressed frustration over the lack of resources for the D.D. client. In many cases, inappropriate resources (e.g., nursing homes) were being utilized simply because appropriate ones were not available. Three mentioned that problems have occurred when D.D. clients and geriatric persons were mixed in nursing homes. This 'mixing' has been criticized by physicians

and relatives of the aged nursing home residents.

Four workers felt additional staff was needed so that more time could be devoted to D.D. clients. Two expressed the belief that workers should specialize in work with the D.D. rather than having to handle all types of cases (e.g., AFDC, Child Welfare, etc.). One complained of professional isolation (i.e., lack of peer support and consultation). Two complained about difficulty in securing authorization to travel outside of their own county.

Three mentioned problems in finding foster homes. These problems were interrelated with the low level of foster home payments and licensing requirements. Two workers expressed uncertainty or confusion related to the D.D. person's legal rights in protective services (trusteeship, guardianship).

Several of the workers expressed a need for a more highly coordinated effort between the Department of Institutions and S.R.S. with regard to release and placement procedures and follow along services.

Placement and Follow Along

At the time of this writing the procedures relating to the placement of BRS&H residents into community programs leave something to be desired. The rather complex transfer of placement and case management responsibility from BRS&H to the S.R.S. Community Services Division and then to social service personnel at the county level can hamper the continuation of client programming begun at BRS&H and result in an inadequate exchange of information needed for proper placement and follow along activities.

To the greatest extent possible, channels and procedures for communication between BRS&H social service personnel and SRS county social service staff must be simplified and streamlined so as to facilitate the direct and rapid exchange of relevant client information.

Persons who have spent many years in BRS&H frequently develop patterns of behavior which are 'functional' within an institutional setting but inappropriate in the community. To a great extent, successful functioning in a community is contingent upon the elimination of the maladaptive behavior learned in the institution.

Those responsible for providing follow along services should have a good understanding of the developmentally disabled, D.D. services and the modification of maladaptive behavior.

Proper placement depends upon the availability of detailed knowledge of the individual's service needs, wants and behavior. Proper client programming and follow along requires frequent contact with the individual coupled with an ability to assess his progress and initiate needed modification.

UNMET SERVICE NEEDS

A 1975 survey conducted by personnel of the Montana Social and Rehabilitative Services Developmental Disabilities Bureau indicated that a great many persons with mental retardation and other developmental disabilities have unmet service needs. The survey data were gathered from interviews with personnel working within the Western Montana Child Development Center, the Bureau of Indian Affairs and various service programs under the

auspices of public health, public welfare and public schools systems. The following table presents the number of noninstitutionalized developmentally disabled individuals, both children and adults, needing specific types of residential services in seven Western Montana counties. Not included in this count were those persons already receiving appropriate services.

RESIDENTIAL SERVICES NEEDED

	Group Home	Foster Home	Group Home or Foster Home	Skilled Nursing Care	Treatment Center
Flathead	58	7	0	7	10
Lake	50	3	10	0	25
Lincoln	15	4	0	1	10
Mineral	1	0	0	0	0
Missoula	18	7	10	5	20
Ravalli	10	0	0	0	10
Sanders	40	7	0	0	10
Total	192	28	20	13	85

The table shown below presents the number of noninstitutional, developmentally disabled Western Montana citizens, both adults and children, known to need selected supportive services. Because many individuals need more than one such service, this is not an unduplicated count. Each entry can be viewed as units of service needed.

see chart on the following page

	SUPPORTIVE SERVICES NEEDED						
	Occupational and/or Physical Therapy	Day Care	Sheltered Employment	Recrea-tion	Transpor-tation	Respite Care	Other Services
Flathead	39	48	80	81	76	23	14
Lake	30	10	70	150	150	20	95
Lincoln	15	15	40	40	35	15	14
Mineral	4	1	--	4	4	1	19
Missoula	43	45	48	103	75	46	--
Ravalli	10	20	25	19	20	30	--
Sanders	30	40	40	70	30	15	--

UNMET EDUCATIONAL NEEDS

According to data gathered by the Regional Services Plan for the Handicapped, approximately 447 school age mentally retarded youth participated in special education programs provided by Western Montana school districts during 1975. Of these, 373 were in EMR programs and 74 were in TMR programs.

Clearly, a great many other mentally retarded youth are in need of special education services but not receiving them. A 1974 survey indicated that approximately 585 students enrolled in Western Montana schools were retarded but not receiving needed educational services. Not included in this count were retarded children of preschool age and those who had 'dropped out' and no longer enrolled in school. On the basis of these data alone, it would appear that a three or four-fold increase in special education services is needed.

PREVALENCE OF MENTAL RETARDATION

Those involved in the planning of a comprehensive system must necessarily attempt to estimate the number of retarded citizens who are potential users of community based services. This raises the issue of prevalence.

It is commonly assumed that approximately three percent of the general population is mentally retarded. The National Association of Retarded Citizens (NARC) and the President's Committee on Mental Retardation (PCMR) are but two of the many organizations which base their program and service recommendations on the three percent prevalence rate. However, not everyone accepts the three percent figure. Mercer (1973) for example, has argued that the three percent rate is based on faulty statistical and definitional assumptions and does not conform to empirical data. She believes the prevalence rate is closer to one percent. Edgerton, Eymon and Silverstein (1975) observe that:

> It may be correct to state that three percent of the children born will be diagnosed as retarded at some time during their lives. But this is not true on any given date; the correct figure is closer to one percent. This is so because people who were diagnosed as mildly retarded during childhood or adolescence appear to be quite normal as adults. Similarly, it is often difficult to identify mildly retarded preschool children because their behavior is often like that of other children. Mental retardation should not be considered an unchanging or a permanent condition. (p. 63)

While the debate on prevalence continues, one can only conclude that the prevalence of mental retardation is somewhere between one and three percent of the general population. If we apply these prevalence rates to the state of Montana which had a 1970 population of 694,409 we find that

between 6,944 (1%) and 20,832 (3%) Montana citizens were mentally retarded. A two percent rate yields an estimate of 13,889. When these same rates are applied to Montana's 1974 estimated population of 735,000, we find that the probable number of retarded individuals is between 7,350 (1%) and 22,050 (3%). The two percent rate (2%) yields an estimate of 14,700.

In the table below, the 1%, 2% and 3% rates have been applied to the 1974 estimated populations of seven Western Montana counties.

County	population estimate	1% prevalence	2% prevalence	3% prevalence
Flathead	42,600	426	857	1,278
Lake	16,700	167	334	501
Lincoln	17,000	170	340	510
Mineral	3,600	36	72	108
Missoula	63,700	637	1,274	1,911
Ravalli	17,900	179	358	537
Sanders	7,800	78	156	234
TOTAL	169,300	1,693	3,391	5,079

For the purpose of this study, projections will be based on the 2% prevalence rate. Within a mentally retarded population (i.e., all persons considered to be mentally retarded) it is commonly estimated that 89% are mildly retarded, 6% are moderately retarded, 3.5% are severely retarded and 1.5% are profoundly retarded. When these percentages are applied to the Montana's 1974 estimated mentally retarded population of 14,700 (2%) further estimates by level of retardation are possible.

Mildly retarded	13,083
Moderately retarded	882
Severely retarded	515
Profoundly retarded	220
TOTAL RETARDED POPULATION (MONTANA)	14,700

Below, the same procedure has been applied to the 1974 estimated retarded population in Region V counties.

County	Mentally Retarded Population, all ages (2% estimate)	LEVEL OF RETARDATION			
		mild (89%)	moderate (6%)	severe (3.5%)	profound (1.5%)
Flathead	857	762	51	30	13
Lake	334	297	20	12	5
Lincoln	340	303	20	12	5
Mineral	72	64	4	3	1
Missoula	1,274	1,134	76	45	19
Ravalli	358	319	21	13	5
Sanders	156	139	9	6	2
TOTAL*	3,391	3,018	201	121	50

*Because calculations were rounded off to the nearest whole number, slight variation in totals are to be noted.

CHARACTERISTICS OF THE STUDY POPULATION: YOUTH AND THEIR PARENTS

In order to gather information which would provide an overview of problems and issues related to deinstitutionalization and the development of community based services in Western Montana, four groups of retarded youths and their parents or parental surrogates were studied. Group I consisted of fifteen BRS&H residents; Group II included the thirteen youths who had been placed out of BRS&H (i.e., former BRS&H residents); Group III consisted of eight youths who had been evaluated at BRS&H but not admitted to the institution; and Group IV was made up of 25 retarded youths who had never utilized any BRS&H services. Altogether 61 youths and their parents made up the basic study population.

CHARACTERISTICS OF YOUTH

Level of Retardation

As might be expected, the youths who were severely and profoundly retarded were those most likely to be institutionalized. Those who are retarded to a lesser degree can usually remain in the community. The levels of retardation for the 61 youths in the study population are shown below. It is noteworthy that 11 of the 15 BRS&H residents (Group I) were either severely or profoundly retarded whereas none of those in Group IV (those who had never utilized BRS&H services) were retarded to this degree.

	GROUP I (BRS&H)	GROUP II (P.O.)	GROUP III (EVAL)	GROUP IV (NEV)	TOTAL
MILD	3	1	3	10	17
MODERATE	1	3	1	10	15
SEVERE	2	4	1	5	12
PROFOUND	9	5	2	0	16
UNKNOWN	0	0	1	0	1
TOTAL	15	13	8	25	61

Age

The mean age of the 61 youths was 15.4. The youngest was 1½ and two were age 5. All others were over eight years of age. A total of 21 were legally adults, i.e., over age 18.

The mean age for groups I, II and IV were 15.8, 16.4 and 15.7 respectively. Youths in Group III, those who had been evaluated at BRS&H, were somewhat younger. Mean age for this group was 11.8 years.

Sex

Of the 61 youths, 35 were males and 26 were females. This distribution reflects the common research finding that males are more likely to be classified as being mentally retarded and more likely to be institutionalized.

Seizures

Twenty-one of the 61 were subject to seizures. Many of the seizure patterns were controlled by medication. The 21 persons having seizures were fairly equally distributed across the four groups. However, data

available to the researchers indicated that those with very severe, frequent and uncontrolled seizures were more common to those who had been institutionalized (Groups I and II).

Cerebral Palsy

A total of eight youths in the study population had cerebral palsy in addition to being mentally retarded. Six of these were in Group IV, those who had never utilized BRS&H services. Among the eight youths, no relationship existed between the presence of cerebral palsy and severity of mental retardation.

Hearing and Sight

Eleven youths in the study population had hearing problems. Two were totally deaf and two others had very limited hearing. Three youths were totally blind and two others had only limited sight. A total of 21 had significant sight problems. Three individuals were both deaf and blind. As might be expected most of those with severe hearing and sight problems were in Group I and II, i.e., BRS&H residents or former residents who had been placed into nursing homes.

Speech Problems

Forty-seven of the 61 youths did not have speech which could be easily understood. Eighteen of these could only make sounds and one was incapable of making sounds. Twenty-two had speech which was 'somewhat difficult' to understand and six had speech which could be termed 'very difficult' to

understand. Ten of the 15 BRS&H residents had rather severe speech problems. As might be expected, persons in Groups I and II, those who had been institutionalized, tended to be among those with the most severe speech problems.

The available data indicated that a significant number of the youths needed speech therapy or assistance in language development. Of the 61 youths studied, 17 needed speech services but were not receiving them. Ten of these 17 were BRS&H residents.

Most of the Group IV youths needing speech services were obtaining some assistance through special education programs. Twelve of the 25 youths in this group were making use of speech programs. However, two others needing the service had not obtained it.

Mobility

Forty-six of the 61 youths could walk without assistance. Over one-half of these were in Group IV. However, only 10 of the 15 BRS&H residents could walk without assistance.

A total of 15 had mobility problems. Five were completely non ambulatory. Of the 25 retarded youths in Group I, those who had never utilized BRS&H services, only two had mobility problems.

Toilet Training

Thirty-eight of the 61 youths were completely toilet trained and never had toilet accidents. All others were incompletely toilet trained. A total of ten youths were not toilet trained at all. Three of these were BRS&H residents, two were in nursing homes and five lived with their parents.

Multiple Handicaps

Twenty-two of the 61 could be described as having multiple handicaps, i.e., having at least one significant handicap in addition to being mentally retarded. One BRS&H resident, for example, was mentally retarded, non ambulatory, blind, deaf and non verbal. Another was retarded, blind, non verbal and experienced severe seizures. Only three of the 15 BRS&H residents studied did not have a significant handicap in addition to mental retardation, usually at the severe or profound level.

Six of the 13 in Group II (former BRS&H residents) and three of eight in Group III had multiple handicaps. It is significant to note that only two of the 25 in Group IV (those who had never utilized BRS&H services) had multiple handicaps. Clearly, the utilization of BRS&H is associated with the existance of multiple handicaps in addition to severe and profound levels of retardation. Needless to say, institutional depopulation and the prevention of institutionalization depends upon the existance of community based programs which can serve the multiply handicapped mentally retarded person.

CHARACTERISTICS OF THE PARENTS

The indepth interviews with parents usually lasted from one and one-half to five hours. One lasted nearly eight hours. Twenty-seven were joint interviews, i.e., with both parents. Nineteen were with the mother only and three were with the father only. Thirteen combined the use of the telephone and the mail as a means of covering all areas of the interview schedule.

Age and Ethnicity

At the time of the interviews, most of the parents were in their 40's. The oldest parent interviewed was a father, age 70. The youngest was a mother 25 years old. The average age for the mothers and fathers in each of the four groups is presented below.

MEAN AGE OF PARENTS

	GROUP I	GROUP II	GROUP III	GROUP IV
Mothers	42.9	44.6	38.4	44.2
Fathers	42.5	50.3	42.1	48.2

Only five of the parents in the 61 families were members of an ethnic minority. Four were Chicano and one was Native American. Even though the Flathead Indian Reservation is part of Region V only two Native American retarded youths fell within the bounds of the study population.

Marital Status and Family Size

Of the 61 families studied the vast majority were married. One was a widow, four were divorced and two were separated.

The four groups did not differ significantly in family size. Family size did not appear to be related to whether or not a retarded family member was placed in the BRS&H. Only two of the families were single child families and five were two child families. Sixteen had three children, sixteen had four and thirteen had five children. Nine families had six or more children.

Educational Level and Occupation

Most of the mothers and fathers had completed high school. The parents' educational level was not related to the institutionalization of a family member. Of the 54 fathers on whom data were obtained, 12 had a grade school education, five had some highschool and 20 had not gone beyond high school. Eight had some college and nine had graduated from college. Of the 60 mothers on whom educational data were obtained, four had some grade school, ten had some high school, 25 had not gone beyond high school, four had completed a three year nursing program, 11 had some college and six were college graduates. Occupational data were obtained on 56 of the 61 fathers. A classification of their occupations appears below.

Professional, Technical and Kindred Workers	8
Managers, Officials and Proprietors	7
Farm or Ranch Owners or Managers	8
Clerical and Kindred Workers	1
Craftsmen, Foremen and Kindred Workers	9
Operatives (e.g., Mechanics, Sawyers, Truck Drivers)	10
Unskilled Service and Labor	9
Retired	2
Disabled Workers	2
	56

A majority (41) of the mothers were full time housewives. Others were involved in teaching, nursing, clerical work, and waitress work. Ten mothers combined full or part time employment with the role of housewife.

County of Residence

Of the parents interviewed 15 were from Missoula County, 13 were from Flathead County, four were from Lincoln County, eight were from Lake County, 10 were from Ravalli County, four were from Sanders County, and

two were from Mineral County. Four of the parents interviewed were living in other counties but were included in the study population because they had recently moved from the Western Montana region.

FINDINGS DERIVED FROM PARENT INTERVIEWS AND OTHER SOURCES OF CLIENT/FAMILY DATA

Included in this section are findings and observations derived from the indepth interviews with parents of 61 retarded youths and from data gathered from BRS&H staff. This data, plus that presented in previous sections, provide the basis for the recommendations presented in the final section of this report.

LIVING ARRANGEMENTS

The 61 retarded youths in the study population were in several different types of living arrangements. Fifteen, of course, were residing at the BRS&H. Living arrangements for the four research categories are shown below.

LIVING ARRANGEMENT	RESEARCH CATEGORY				
	Group I (BRS&H)	Group II (P.O.)	Group III (EVAL)	Group IV (NEV)	Total
BRS&H	15	0	0	0	15
Parents' Home	0	5	6	23	34
Foster Home	0	3	0	1	4
Nursing Home	0	4	0	0	4
Group Home	0	0	1	0	1
Another Institution (out of state)	0	1	0	0	1
Semi-independent	0	0	1	1	2
Total	15	13	8	25	61

Slightly more than one-half of the 61 were living with parents. It is also noteworthy that of the 13 who were placed out of BRS&H (Group II),

five returned to their parents' homes while eight went into other settings. Assuming these data are representative it would appear that only a minority of youths placed out of BRS&H would be able to return to their parents' homes. Deinstitutionalization, therefore, is contingent upon the development of alternate living arrangements.

PARENT'S SATISFACTION WITH CHILD'S LIVING ARRANGEMENT

All of the parents were asked how satisfied they were with their child's current living arrangements. Below are their responses.

	GROUP I (BRS&H)	GROUP II (P.O.)	GROUP III (EVAL)	GROUP IV (NEV)	Total
Very Satisfied	4	1	5	19	29
Satisfied	6	5	1	5	17
Dissatisfied	4	2	1	1	8
Very Dissatisfied	1	4	1	0	6
No Opinion	0	1	0	0	1
Total	15	13	8	25	61

The greatest amount of dissatisfaction was expressed by parents in Group II, i.e., those whose children had been placed out of BRS&H.

PARENT'S PREFERRED LIVING ARRANGEMENT

Forty-two of the parents did not want a change in their child's living arrangement whereas 19 wanted a change. The living arrangements preferred by these 19 parents are shown below.

see chart on the following page

PREFERRED LIVING ARRANGEMENT	GROUP I (BRS&H)	GROUP II (P.O.)	GROUP III (EVAL)	GROUP IV (NEV)	Total
Group Home	2	2	1	2	7
Foster Home	1	0	0	0	1
Nursing Home	2	1	0	0	3
BRS&H	0	1	0	0	1
Institution (not BRS&H)	2	0	1	0	3
Treatment Center	0	1	0	0	1
Not Sure	1	2	0	0	3
Total	8	7	2	2	19

Fifteen of the 19 parents wanting a change for their child were from Group I and Group II, those whose child was at or was previously at BRS&H. It is important to note that none of the 19 wanting a change wanted their child returned to their home.

Several parents indicated that they would like a change in their child's living arrangement but would support a change only if they were assured that the change would result in better care for their child. A number of parents expressed doubt over the ability of community based services to properly care for their child.

COMPARISON OF BRS&H PROJECTED LIVING ARRANGEMENT AND PARENT'S PREFERRED LIVING ARRANGEMENT

Fifteen youths in the study population were residing at BRS&H (Group I). After an assessment of these individuals, BRS&H staff formulated a 'projected living arrangement' for each, i.e., the most suitable arrangement for the individual if he/she were to leave the institution. When these projections were compared to the parents' preferred living arrangement, it

was found that the two agreed in only four of the fifteen cases.

In seven cases, the parents did not want their child to leave the institution. For these seven individuals, BRS&H staff recommended a foster home for five, a group home for one and a treatment center for the seventh. Eight parents stated that they would like their child out of BRS&H. In four cases, BRS&H staff and parents agreed on the preferred living arrangement. In two cases, parents wanted their child in a skilled nursing home while BRS&H staff preferred foster home placements. In two cases, parents wanted their child in another institution (not BRS&H) while BRS&H staff preferred to see one of these youth in a treatment center and the other in a foster home.

PARENT'S VIEWS OF PLACEMENT OUT OF BRS&H

Group I and Group II parents were asked their views on the placement of their child out of the BRS&H. Of the 15 who had children in BRS&H, seven were 'very favorable,' three were 'favorable,' and five were 'opposed.' Many of those who felt favorably disposed to the idea of their child leaving the institution qualified their answer by saying that they would favor the move if they knew that the community based programs were stable and had more to offer than the institution. Of the thirteen whose children had already been placed out of BRS&H, eight felt 'very favorable,' one was 'favorable,' one was 'opposed,' two were 'very opposed' and one offered no opinion.

PARENT SATISFACTION WITH BRS&H

The parents of the 28 youths who either resided at BRS&H or had been placed out of the institution were asked how satisfied they were with the

care, treatment and training their child had received. Their responses were as follows.

	GROUP I (BRS&H)	GROUP II (P.O.)	Total
Very Satisfied	4	1	5
Satisfied	6	5	11
Dissatisfied	4	2	6
Very Dissatisfied	1	4	5
No Opinion	0	1	1
Total	13	15	28

A fairly common complaint expressed by these two groups of parents was that they lacked sufficient and continuous contact with the BRS&H staff. The high rate of staff turnover at the institution made it difficult for some of the parents to maintain a relationship with staff who could explain what was happening to their child. Because of the publicity BRS&H has received, many feared that their child would be physically or sexually abused by other residents. Some Group II parents complained that they were not involved in the decision to place their child out of the institution.

REASONS FOR INSTITUTIONAL PLACEMENT

The parents identified a number of reasons for their decision to institutionalized their retarded child. As might be expected, most gave more than one reason. Reasons for placement are presented on the following page.

REASONS FOR PLACEMENT	NUMBER OF TIMES MENTIONED
Professionals encouraged placement	23
Strain on the family	19
Child needed services that were not available in the community	17
Strain on other children in the family	16
Could no longer cope with the problem	13
Child needed round-the-clock medical care	9
Child suffered rejection in the community	7
Strain on the marriage	7
Financial problems	6
Services available in the community were of poor quality	3

CHILD'S AGE AT INSTITUTIONAL PLACEMENT

Twenty-eight of the 61 retarded persons in the study population had been institutionalized (i.e., those in Groups I and II). Age of first placement is shown below.

AGE OF FIRST PLACEMENT	NUMBER OF RETARDED PERSONS INSTITUTIONALIZED
Shortly After Birth	3
Age 1½ to 3 Years	8
Age 4 to 6 Years	4
Age 7 to 9 Years	5
Age 10 to 13 Years	5
Age 14 to 16 Years	3
Total	28

Since institutionalization is essentially a family decision, the age of placement is a crude barometer of family stress and frustration. It is important to note that over one-half of these placements occurred prior to age six and most of these were strongly encouraged by professionals. In the past, few services have been available to this age group. Early intervention and preschool services hold promise as a deterrant to institutionalization.

PARENT'S AGE AT PLACEMENT

Most of the 26 Groups I and II parents were in their mid or late 30's at the time they placed their child at BRS&H. The mother's age at the time of placement ranged from 22 to 46 years with a mean age of 34. The father's age at the time of placement ranged from 24 to 58 years with a mean age of 38.2.

REASONS FOR NOT INSTITUTIONALIZING THE CHILD

Of the study population, 33 had not been institutionalized. Several questions were directed toward the parents in an attempt to identify when the parents considered placement most seriously and why they decided not to institutionalize their retarded child.

Twenty-three of the parents explained that they never seriously considered placement. Ten reported that they had thought very seriously about institutional placement and for five of these it was when their child was between five and nine years of age. While these data are limited, they may point to a period when families are forced to grapple with the placement

decision. For several families this was a period of time when they discovered that their school system had little to offer their child or would not accept him at all. Montana's new mandatory education law will, hopefully, eliminate this problem.

Most of the 33 parents who did not institutionalize their child expressed what can be best described as a "moral commitment" to the care of their retarded child at home. In other words, they rather stoically concluded that they had an obligation to keep their child at home. To place their child would be for them a betrayal of this commitment and parental obligation. It is interesting that many of the parents who opposed institutional placement involved themselves in the development and promotion of programs in their home communities.

PARENT'S VIEWS ON PREVENTION OF INSTITUTIONALIZATION

Group I and Group II parents, those who had institutionalized their child, were asked what community services--had they existed--might have helped them avoid placement. Seven of the 15 in Group I were certain that institutionalization was unavoidable. In other words, they could not conceive of community services which could have helped them to avoid placement. Many of these parents were unfamiliar with existing services or ones which had developed since their placement decision. The other eight Group I parents identified several services which might have helped prevent placement. Among these were community treatment for severe epilepsy, day care, more adequate medical care, special training for the deaf retarded, assistance with behavioral problems and skilled nursing care.

The children of Group II parents had all been placed out of the BRS&H. As compared to the Group I parents, these parents named more services which could have helped them avoid placement. Apparently, they were better informed about alternatives to institutional care. Special education and training in self help skills were mentioned most often. Others said they had needed counseling, financial assistance to pay medical bills, respite care, homemaker service, day care and arrangements for emergency medical care. One would have needed a special community program for the deaf-blind retarded.

OPINIONS ON CLOSING BRS&H

When asked their opinion on the closing of the BRS&H, most parents expressed opposition to such a possibility. Their opinions are shown below.

	GROUP I (BRS&H)	GROUP II (P.O.)	GROUP III (EVAL)	GROUP IV (NEV)	Total
Strongly Favor Closing	4	2	2	5	13
Favor Closing	0	0	0	3	3
Opposed to Closing	5	2	3	7	17
Strongly Opposed to Closing	6	9	3	9	27
No Opinion	0	0	0	1	1
Total	15	13	8	25	61

Many Group I parents opposed the phasing out of institutional care because they could not conceive of any other facility or program being capable of caring for their child. The existence of an institutional

facility apparently provides a sense of security to many parents, even those who have never placed their child and who hope to avoid institutionalization. Interviews with parents of institutionalized youths indicated that many were uninformed about the recent development of community based programs. Parents are likely to oppose the closure of BRS&H until stable and workable alternatives to institutional care exist in the community.

LACK OF SERVICES IN THE COMMUNITY

Many parents complained about the lack of services in their home communities. This was especially true of parents living in or near smaller towns. Perhaps the most dramatic expression of this frustration is the decision to move to another community in order to secure services. Eight of the families in the study had moved in order to obtain needed services. In some cases the move meant moving farther away from relatives and friends and giving up satisfactory employment.

As shown below, 24 of the 61 parents interviewed, reported that they had traveled out of state in order to secure services for their retarded child.

	GROUP I (BRS&H)	GROUP II (P.O.)	GROUP III (EVAL)	GROUP IV (NEV)	TOTAL
Traveled Out of State	4	6	3	11	24
Never Traveled Out of State	11	7	5	14	37
Total	16	13	8	25	61

In most cases, these parents had traveled to Seattle, Spokane or Salt Lake City and sought diagnostic services. Of interest is the fact that 11 of 25 Group IV parents, those who had never utilized BRS&H services, had traveled out of Montana.

There is no one explanation for the tendency to go out of state for diagnostic services. In some cases parents were referred by their physician, others sought out a 'second opinion' and others were not aware of diagnostic services available in the region.

TRANSPORTATION

Twenty-two parents expressed the belief that some type of transportation service was needed for the mentally retarded. Thirty-four did not see a need for this service. Five did not have an opinion on this matter.

Six stated that a lack of transportation was a "very large problem." As would be expected those who were most concerned about transportation were parents in Groups III and IV, or those whose retarded children were still living at home. Nine parents who provided transportation for their child, usually to and from school, drove an average of 170 miles per week. Two parents drive 300 miles per week or 60 miles per day in order to secure educational services.

None of the communities in Western Montana have public transportation services. Aside from private transportation, only taxi service was available to non school age persons. However, some of the larger service programs in the region have mini buses. In a couple of communities a subsidized taxi program has been established by the State D.D. Bureau. School buses are available to many but not all mentally retarded school age children.

FINANCIAL STRAIN

All of the parents interviewed were asked if securing services for their retarded child had created financial strain. A breakdown of their answers is presented below.

DEGREE OF FINANCIAL STRAIN	GROUP I (BRS&H)	GROUP II (P.O.)	GROUP III (EVAL)	GROUP IV (NEV)	Total
Great Strain	4	1	2	4	11
Some Strain	5	4	3	9	21
Little Strain	1	2	1	4	8
No Strain	5	5	2	8	20
No Opinion	0	1	0	0	1
Total	15	13	8	25	61

As can be seen a total of 11 experienced "great financial strain" and 21 experienced "some financial strain." Seventeen of the 61 parents reported that a lack of adequate income had prevented them from securing needed services for their retarded child. The others did not feel that a lack of money was a factor in keeping their child from needed services.

It was noted that many parents showed a reluctance to utilize what they termed "welfare programs." While they did not hesitate to utilize public school or public recreational programs, a 'stigma' was attached to public assistance and public social service programs. The use of a means test or financial eligibility criteria in the latter programs discouraged their utilization.

SATISFACTION WITH EXISTING COMMUNITY SERVICES

A rather surprising finding was the fairly high level of satisfaction parents expressed for the few community programs that do exist in the region. In many cases, the parents seemed more satisfied with the programs than the professionals who operate them. This discrepancy seems related to the concept of 'relative deprivation.' In other words, the parents seem satisfied because they did not possess a basis for comparison. Some parents explained their satisfaction by saying that existing services are "better than nothing" and they had "nothing" just a few years ago. Parents who had previously lived in other states or metropolitan areas were more likely to express dissatisfaction with programs in the region than those who had never lived out of the region.

Some parents expressed concern over the quality of service provided by community based programs. It would appear that some parents will resist deinstitutionalization until they are convinced that community programs provide service that is equal to or better than that available in institutions. In view of the fact that some deinstitutionalization efforts (e.g., the overuse of nursing homes) have been minor disasters, their concerns are understandable. The existence of stable programs of high quality will do much to build confidence in community alternatives.

FEARS OVER PROGRAM PERMANENCE

Many parents and some community professionals are opposed to deinstitutionalization because they doubt the stability of community based programs. They wonder whether the state and federal governments are truly committed

to the ongoing funding of such programs. Many fear that deinstitutionalization is a 'fad' and that future budget cut backs might leave them without either an institution or community based programs. Given the recent history of other human service programs (e.g., mental health, war on poverty programs, etc.), this is a legitimate concern.

KNOWLEDGE AND UTILIZATION OF EXISTING SERVICES

All of the parents interviewed were questioned regarding their knowledge and utilization of existing services and programs. In relation to a list of programs parents were asked if they: (1) were now using the service, (2) had used the service in the past, (3) were aware of the service but had not used it, or (4) were not aware of the service. Many of the parents had "heard of" or were vaguely aware of existing programs but were uninformed regarding specifics such as eligibility, cost, availability, location or the exact nature of the services. Because service terminology was often unfamiliar or confusing to the parents, much interview time was spent explaining the services. Many parents expressed a need for further information on the services discussed.

Responses provided by the parents are shown below. It should be noted that in the case of some joint interviews, the two parents gave different responses. For this reason the number of responses sometimes exceeds 61. Questions concerning services peculiar to a city were only asked of parents in that city.

PROGRAM, AGENCY OR TYPE OF SERVICE	Now Using This Service	Have Used This Service In Past	Aware of Service But Have Not Used It	Not Aware of This Service
Child Development Center (Missoula)	8	28	20	8
Missoula Crippled Children and Adult Rehabilitation Center	1	8	41	11
Community Mental Health Center	1	11	36	14
Community Coordinated Child Care (4C's)	0	0	17	40
State Social and Rehabilitative Services (SRS)	6	6	36	15
State Rehabilitative Services (Vocational Rehabilitation)	4	6	46	6
Department of Public Welfare (Social Services and Economic Assistance)	9	9	41	3
County Department of Health	2	18	35	6
Crippled Children's Division--State Department of Health	1	4	35	23
Family Planning/Planned Parenthood	0	0	54	9
Public Schools (Special Education)	31	11	21	0
University of Montana Clinical Psychology Center	0	14	29	21
University of Montana Speech and Hearing Clinic	1	18	32	12
Boulder River School and Hospital	17	18	28	1
Eastmont Training Center (Glendive)	0	1	28	33
Warm Springs State Hospital	2	20	40	3
State School for Deaf and Blind (Great Falls)	0	1	54	8
Montana Center for Handicapped Children (Billings)	1	6	32	24
Indian Health Service	1	0	38	23
Shodair Crippled Children's Hospital (Helena)	0	3	49	11
Association for Retarded Citizens	18	10	20	16
Western Montana Epilepsy Association	0	0	37	30
Council for Exceptional Children	0	1	17	46

	Now Using This Service	Have Used This Service In Past	Aware of Service But Have Not Used It	Not Aware of This Service
Association for Children With Learning Disabilities	0	1	14	48
Parents of Exceptional Children	0	0	22	41
Medicaid	12	3	38	9
Supplemental Security Income (SSI)	6	1	32	24
Food Stamps	7	7	46	2
Aid to Families With Dependent Children (economic assistance)	4	5	39	13
County General Assistance	0	4	37	21
Missoula Area				
Ivy Street Arts and Crafts	0	0	9	36
Opportunity Foundation Workshop	0	3	28	14
Mary Dawson's Program	0	0	13	32
Arrowhead Home (group home)	0	1	20	24
L'Arche Group Home	0	0	16	29
Kalispell Area				
Flathead Industries	0	1	26	13
Adults Group Home	0	0	19	21
Day Activity Center	0	0	14	28
Libby Area				
Special People's Program	0	0	7	27
Polson-Ronan Area				
Special Citizens Center	2	0	11	22
St. Joseph's Convalescent and Retirement Center	0	0	17	18

It is noteworthy that public programs (e.g., public health, public schools, public welfare, state hospitals, etc.) were among the best known programs. As might be expected, special education was the most utilized service. Of the various parent or self-help organizations listed, the Association for Retarded Citizens was the best known and most utilized.

CONFUSION OVER SERVICE TERMINOLOGY

It was observed that most parents and many providers lacked a clear and uniform terminology. Different terms or service descriptions mean different things to different people. For example, several programs termed "sheltered workshops" were, in reality, work activity centers.

INFORMATION AND REFERRAL (I & R)

When asked about the need for an information and referral service, 44 of the 61 sets of parents stated that an I & R service would be of "very great importance." Eight rated it as being of "great importance," seven thought it would be of "some importance" and two expressed no opinion. The value placed on I & R was not apparently related to the research group. Twelve of the 15 parents whose children were in BRS&H (Group I), for example, considered I & R to be of "very great importance."

RESPITE CARE

Throughout the region there is inadequate part time or respite care for retarded persons and their families. A lack of respite care often prevents the parents and other family members from working, responding to

emergencies and obtaining periodic relief from the demands of parenting.

All of the parents were asked about the need for respite care services and how important such services would be to families having a retarded member. These responses are shown below.

	TOTAL	GROUP I (BRS&H)	GROUP II (P.O.)	GROUP III (EVAL)	GROUP IV (NEV)
Very Great Importance	34	9	8	4	13
Great Importance	6	3	2	1	0
Some Importance	15	2	2	2	9
No Importance	6	1	1	1	3
Total	61	15	13	8	25

It is clear that adequate respite care services would help some families to avoid institutional placement. Respite care is possibly one of the least expensive community based services that can be developed and also one which is highly effective in reducing strain on families.

TRAINING AND EDUCATION

Of the 61 youths in the study population, only 38 were receiving some type of special education or training. Thirty-two were in community programs and six were in a program at BRS&H. Nine of the 15 BRS&H residents and 14 of those living in the community were not in training or educational programs.

Only three of the parents interviewed expressed the belief that their child did not need educational services. These three were parents of very

severely handicapped youngsters. Eight expressed great dissatisfaction with the fact that nothing was available for their child.

Most of the services in the region were EMR programs. Only a few schools provided TMR programs. There appeared to be wide variation among the education/training services available to retarded youths living in the community. Some children were involved in well developed, full day, five day a week programs whereas others attend school for one or two hours per day for purely social purposes. It would appear that some schools view the provision of special education as an unessential service rather than a necessary and integral part of a total school program.

Several of the mentally retarded youth interviewed during the course of this research project expressed anxiety about being in a special education class and being segregated from other classes attended by "normal" children. All felt that being in a special class labeled them as a "dummy."

COUNSELING SERVICES

All of the parents interviewed were asked several questions about counseling services for themselves and their retarded child. A substantial number of parents in all four research groups expressed confusion about counseling. They were uncertain what counseling was and even when it was explained by the interviewer, some were still unsure whether they had, in fact, ever received counseling. Several parents associated counseling with having serious emotional problems or "being crazy." It is likely that many parents have failed to seek professional counseling because of the stigma they have attached to such services.

Of the 61 sets of parents interviewed, 46 reported that their retarded child was not receiving counseling services and 26 of the 46 were not sure whether such service was needed. Only 15 of the 61 parents reported that their retarded child was receiving counseling and this included five parents who simply presumed that their child was receiving counseling at the BRS&H. Most of the other 10 reported that their child was receiving counseling from public school personnel.

When asked about counseling services for themselves, only seven parents reported that they were currently receiving counseling services. Of the 54 who were not receiving counseling services, six expressed an immediate need for counseling, eight felt they would need counseling in the future and 17 believed that counseling services would not be needed. Twenty-three were unsure about their need for counseling.

Given the many frustrations and problems revealed by the parents during the interviews, it appeared that many parents would benefit from appropriate and relevant counseling services. Unfortunately, most parents were not receiving counseling and many have not sought such services.

The parents who had received counseling were also asked how satisfied they were with the counseling. This question yielded very mixed responses. Some were fairly satisfied and some were quite dissatisfied. Their satisfaction or dissatisfaction seemed unrelated to the profession of those who had provided the counseling. This is consistent with the conclusion reached by Wolfensberger. After a review of literature related to parent-professional relationships, dissatisfaction with professionals commonly expressed by parents and the claims of expertise by various professional disciplines,

Wolfensberger (1967) suggests that a counselor's professional affiliation is irrelevant:

> I suggest that a counselor's professional affiliation is irrelevant. Possession of a medical or any other degree neither qualifies nor disqualifies a person from counseling and managing parents. Instead, the following criteria are proposed as relevant: (1) knowledge of the broader medical, social, educational, habilitational, behavioral, etc., aspects of retardation; (2) knowledge of resources in the broadest sense (i.e., agencies, services, long-range local prospects, reading materials, "gadgets" useful in home management, etc.); (3) competency, acquired through training, in counseling principles and techniques in general; (4) experience in the applied-clinical area of retardation; (5) freedom from stereotypes about retardation; (6) possession of genuinely positive attitudes toward retardation, the handicapped, and their parents; (7) an orientation to the current community centered management approach; (8) a sensitivity to the reality needs of the family; (9) willingness to go beyond traditional approaches to help parents, even at the cost of personal convenience; and (10) great patience. (p. 355)

SHELTERED WORKSHOP AND SHELTERED EMPLOYMENT SERVICES

Only three of those in the study population were participating in a sheltered workshop or employment program. This was undoubtedly related to the fact that this Project focused on children and youths. It was interesting, however, that five parents felt an immediate need for this service and 27 assumed their child would need such a program in the future. Thirteen parents expressed the belief that their child would never need this service and another 13 expressed uncertainty about this need. This seemed related to the low expectations some parents had for their retarded child.

Quite a few of the parents expressed confusion over workshop and sheltered employment services. Many, for instance, tended to equate work activity with sheltered workshops' services. Few parents seemed aware of other work-related options such as sheltered work stations in regular

commerce and industry, on the job training, etc.

EVALUATION AND DIAGNOSTIC SERVICES

Evaluation and diagnostic services were probably the one service area which was least understood and most confusing to parents. All had utilized some type of evaluation/diagnostic service but many expressed uncertainty about whether it had been adequate and whether additional evaluation was needed.

Only four parents were of the opinion that further evaluation was not needed. Fourteen felt an immediate need for evaluation/diagnostic services and 15 wanted additional diagnostic workups for their children in the near future. The other 28 expressed confusion and uncertainty about the need for this service.

The high degree of confusion surrounding evaluation/diagnostic services is undoubtedly related to the fact that this is one of the more technical service areas and one farther removed from their own life experience. Also, it is probably related to the emotional impact of a diagnostic workup. Several parents complained that professionals did not spend enough time explaining the diagnostic findings or used terminology they could not understand.

Some parents were fairly satisfied with the initial diagnostic/evaluation services they had experienced. Those who were not tended to continue to 'shop around' and seek out other professional opinions. Whether or not the parents seemed satisfied appeared to be related, in part, to the counseling and guidance they received at the time of the diagnostic workup and the amount of time the professional(s) had spent with them.

MEDICAL CARE

All but two of the 61 sets of parents reported that their child was receiving medical care. Aside from those receiving medical services at the BRS&H, all other retarded persons in the study population received medical care from a physician (usually a general practitioner) in their home community or in a nearby community.

Most of the parents reported satisfaction with the medical care they had secured for their child but many reported that they had to 'shop around' in order to find a physician who seemed accepting of and interested in their retarded child. Judging from reports provided by parents and information gathered from BRS&H staff, it appears that many physicians are not well informed about the developmental disabilities (especially seizure disorders). The tendency of some physicians to encourage institutional placement rather than assist the family to explore alternatives to institutional care indicates that they lack knowledge about community based programs or are unnecessarily pessimistic about mental retardation.

DENTAL CARE

Of the 61 sets of parents interviewed, 22 reported that their retarded child was not receiving regular dental care. Four of these were parents of youths at the BRS&H.

Many parents of noninstitutionalized youths reported difficulty in finding a dentist interested in providing service to their child. Most parents found a dentist by 'trial and error' or upon the recommendation of

other parents of retarded children. Several parents suggested that some type of register be established as an aid to parents wanting to locate a dentist for their retarded child.

RECREATION

Twenty-three of the 61 individuals studied were involved in recreation services. Twelve of these were reportedly obtaining recreation through special education programs, seven were receiving recreation at BRS&H and five were in other programs. A total of twenty-nine youths, including eight at BRS&H and 21 living in the community, were not participating in recreational programs for the mentally retarded. It was not possible to determine if nine of the 61 youths were in programs.

Seventeen of the parents expressed an immediate need for recreational services oriented toward the mentally retarded. Seven parents did not believe recreation was needed by their child and three believed some type of recreational service would be needed by their child in the future.

In discussing recreational services with parents and professionals, it became evident that public programs such as city recreation departments have been reluctant to serve the mentally retarded. This problem seems to exist in spite of the fact that public programs are to serve all citizens.

NARC MEMBERSHIP

Nineteen of the 61 sets of parents interviewed were active members of the National Association for Retarded Citizens. Six others had been NARC members in the past. However, the majority of parents interviewed had never belonged to the NARC.

Of the 25 parents who had institutionalized their child, only two were still NARC members and six others were past members. This finding seems noteworthy when one considers that NARC membership is a highly useful means of keeping in touch with new trends and learning about new community services.

While the data were limited, it appears that there is a direct relationship between NARC membership and a favorable attitude toward deinstitutionalization. Those who were most interested in the development of alternatives to institutional care were usually parents who were active in the NARC. There were some indications that parents of institutionalized children avoided NARC meetings because the emphasis given to community services made them feel guilty for having placed their child in an institution.

RECOMMENDATIONS

PLANNING, PROGRAM DEVELOPMENT AND SERVICE COORDINATION

Recommendation. In keeping with modern trends, the goals and design of programs and services should conform with the developmental model and principles of normalization.

Recommendation. Persons involved in the planning and operation of services and programs should receive special training in normalization principles and developmental concepts.

Recommendation. To the greatest extent possible developmentally disabled persons, parents and parent group representatives, professionals and interested citizens should participate and share in decision making related to the planning and development of a comprehensive service system in Western Montana. The insights and perceptions of service consumers should not be discounted by professionals and program planners. Neither should the knowledge and experience of professionals be devalued by consumers of service.

Recommendation. In keeping with the principle of normalization, generic services should be utilized wherever and whenever possible. Ideally, the utilization of a service should not require that the consumer be "labeled" mentally retarded or developmentally disabled as a criteria for eligibility.

Recommendation. In order to enhance the coordination of services and increase accountability, the roles and responsibilities of various service providers and agencies, (e.g., BRS&H staff, County Social Service personnel, D.D. Bureau personnel, etc.) should be clearly defined. Statements of

agency roles and responsibilities should be available to parent groups (e.g., ARC Chapters) and other interested persons in a position to monitor services and function as a client advocate.

Recommendation. Since the creation or expansion of programs for the developmentally disabled by nonprofit corporations usually entails an initial outlay of funds (e.g., staff, equipment, space, etc.) prior to reimbursement for purchaseable services by state agencies, sufficient 'start up' funds must be available to these programs during the first months of operation.

Recommendation. Serious study should be given to the desirability and feasibility of creating a single agency in each of Montana's five regions which would provide or coordinate comprehensive medical, educational, social, vocational and other services to the developmentally disabled. (This single agency concept is utilized in many states, e.g., Nebraska, Washington, California, etc.). Such an agency would be responsible for follow along services for the D.D. client and his/her family and also serve as the 'fixed point' for information and referral. This agency would serve as the link between the community and BRS&H. All referrals to and from the BRS&H would pass through the agency. Institutional care would be used only when community alternatives could not be secured. The agency should be highly publicized, visible and accessible. The suggested single agency should be responsible and responsive to a regional board of directors composed of consumers of service, professionals and interested citizens.

It is important to note that there are good arguments for and against the single agency concept. The basic argument in favor of the concept is

that it focuses additional attention and resources on the needs of the mentally retarded and developmentally disabled and should, therefore, result in improved services and a better coordinated service system for this specific group of citizens. A significant argument against the concept is that it creates a 'special agency' and therefore departs from normalization principles which emphasize integration and the utilization of generic services rather than the creation of special services which remove the retarded from the mainstream of the human service delivery system. It can also be argued that the creation of a separate agency further fragments the already fragmented human service system and generates additional competition for the scarce human service dollar.

QUALITY CONTROL OF SERVICES

Recommendation. Community based programs should undergo regular evaluation. PASS-3 and the J.C.A.H., Standards for Community Agencies Serving Persons with Mental Retardation and Other Developmental Disabilities are two approaches which can be used to evaluate and constantly upgrade service quality. Funding should be withdrawn from community programs which fall short of accepted levels of quality.

Recommendation. To the greatest extent possible, programs within the developmental disabilities service system should utilize the same or similar terminology and method of client record keeping. Such uniformity across programs facilitates program evaluation and the monitoring of client progress.

Recommendation. Since parents and interested citizens can be invaluable program monitors and advocates for quality services, ARC Chapters and D.D. Regional Councils should make special efforts to provide these individuals

with information that will help them to assess program quality. Many parents in Nebraska, for example, have been given training in the PASS approach to evaluation. Armed with this conceptual framework they are in a position to offer constructive criticism to professionals and exert pressure toward the upgrading of community services.

ADVOCACY

Recommendation. Citizen advocacy programs should be established to service retarded persons living in the community and for those living at BRS&H. According to the NARC Handbook for Residential Services Committees (1972):

> ...citizen advocacy is concerned with providing the individual with support in coping with the practical problems of everyday life as well as support in the area of his emotional and social needs. The advocacy role should not be exercised by governmental agencies or professionals functioning in their professional capacity, but rather by competent and suitable citizens who are free of relationships which might result in a conflict of interests between the needs of the retarded person being served and the agency providing services to that person. (p. 20)

Recommendation. Both the BRS&H and community based programs should be monitored by an independent advocacy organization which does not depend upon existing agencies or governmental structures for its funding. (Various forms of Citizen Advocacy Programs are described in Wolfensberger and Zauha, Citizen Advocacy, Toronto: National Institute on Mental Retardation, 1973).

COUNTY SOCIAL SERVICES

Recommendation Given the demands of--and broad responsibilities associated with--the placement of formerly institutionalized individuals into the community, county social service departments must be enlarged. It

appears desirable that additional workers specialize in developmental disabilities rather than carrying diversified caseloads.

An alternative to the above would be the creation of a special D.D. agency in each region responsible for follow along and case management. The State of Washington has, for example, utilized this approach.

Recommendation. Since the D.D. service system has been regionalized, county social service workers should be free to travel to other counties and perform necessary tasks without regard to traditional county boundaries and identities.

Recommendation. The availability of relevant in-service training and staff development programs related to D.D. services must be expanded. Required or manditory attendance by county social service workers should be considered. Workloads must be adjusted so as to encourage participation. The acquisition of new skills and knowledge should be rewarded by promotion or salary increases.

PLACEMENT PROCEDURES

Recommendation. To the greatest extent possible the resident, his/her parents and/or other responsible persons directly concerned with the resident's well being should be involved in formulating the placement plan and in formulating goals.

Recommendation. In order to facilitate the direct and rapid exchange of relevant client information necessary for appropriate placement, channels and procedures for communication between BRS&H social service personnel and SRS county social service staff must be simplified and streamlined.

Recommendation. In order to enhance interagency communication, BRS&H staff should make regular visits to community programs. Likewise, county social workers and other providers of community based services should make regular visits to BRS&H. Joint seminars and case conferences should be utilized to exchange case management information. BRS&H and county social service travel budgets must be adequate so as to permit such exchanges.

Recommendation. In order to avoid the disruption of client programming (e.g., programs of behavior modification or skill acquisition) begun at BRS&H and assure a continuity of training methodology, BRS&H staff should be available as consultants to community based providers responsible for serving the formerly institutionalized person.

Recommendation. Prior to the placement of an individual from BRS&H a county social service worker and other relevant community providers should visit and observe the individual at BRS&H and participate in a case review with BRS&H staff. To the greatest extent possible, an individualized case plan should be developed prior to placement. The plan should contain both short-range and long-range goals plus at least one optional plan in case the preferred plan is unsuccessful. This plan should be reviewed and revised within two or three weeks after community placement.

Recommendation. Whenever desired and feasible, the BRS&H resident under consideration for placement should visit the community programs in which he will participate and the community in which he/she will live prior to the final decision on placement from BRS&H.

Recommendation. Serious consideration should be given to the use of a 30 day trial community placement prior to the final decision affecting release from BRS&H.

Recommendation. BRS&H staff should make special efforts to maintain contact with the parents of BRS&H residents, especially the parents of BRS&H residents under consideration for community placement. Ideally, regular personal interviews should be utilized (at least two or three times per year). Letters, telephone calls and newsletters should be used to supplement personal contact with parents. Parents should be provided with current and specific information about their child's progress, service needs, likes, dislikes, etc.

Recommendation. Those concerned with deinstitutionalization need to develop methods of informing the parents of institutionalized persons about community based alternatives to BRS&H. Such methods must be low keyed and nonthreatening. Personal contact is undoubtedly the best method. Parents must not be made to feel guilty for having placed their child in an institution at a time when no alternatives existed or for having followed the advice of professionals who were unaware of alternatives.

Recommendation. Before an individual is placed out of BRS&H, his/her exact legal status should be reviewed and defined. The need for guardianship should be assessed. This assessment should be done jointly by BRS&H staff, County Social Service personnel, parents, citizen advocates and other concerned persons. In all cases the rights of the BRS&H resident should be protected. If a guardianship is deemed necessary, this should be established before BRS&H's responsibility is terminated.

Recommendation. Mentally retarded individuals should not be placed in facilities for the mentally ill except when clearly appropriate for clinical reasons. Similarly, the mentally retarded should not be placed in facilities for the aged unless the mentally retarded person is aged and in need of such programs.

PREVENTION OF INSTITUTIONALIZATION

Recommendation. On the basis of data gathered during the course of this study, it would appear that several strategies might serve to reduce the number of institutional placements from Western Montana. These are: (1) modify the beliefs and attitudes of physicians toward institutional care; (2) develop services (e.g., respite care) which would reduce strain on the family; and (3) develop appropriate community based residential and support services and inform the public and professionals of their existence.

Recommendation. Greater emphasis must be placed on early childhood and preschool training for the mentally retarded child. Infant stimulation programs should also be available. There is also a great need for programs of parent training which will provide parents with skill in the home-based training of their own child.

RESIDENTIAL SERVICES

Recommendation. Special programs for parents, in-home trainers and consultants, respite care and necessary financial assistance should be available to all parents and siblings who desire to keep their retarded child, brother or sister in their own home. Highest priority should be given to the creation of those community services and family support programs which will allow parents to keep their child in their own home for as long as desired and/or culturally normative. Community based residential services should be available to retarded persons who cannot or no longer desire to remain with their parents or natural family.

Recommendation. A wide array of community based residential services should be created (e.g., infant nursery and developmental programs, child development hostels, intensive behavior management units, training hostels, crisis assistance homes, supervised apartments, adoptive homes, foster homes, group homes, etc.). In keeping with normalization principles, the size of these residential services should not exceed that of a large family (e.g., eight persons) and be a typical residence in both appearance and location.

Recommendation. Various forms of group homes and foster homes are among the most needed alternate living arrangements for the mentally retarded now in BRS&H, those who can no longer remain with their parents and those who desire a change in their current living arrangement. Payments available to group homes and foster homes should be raised to a level which will facilitate the development and expansion of these resources.

Recommendation. An aggressive program for foster home recruitment should be launched. Components of the program should include: (1) public service announcements on radio and television; (2) appearances on "talk" and news shows; (3) brochures distributed in public buildings, churches, shopping centers, etc.; (4) speeches given at high schools, universities, service clubs, etc.; (5) word of mouth by present foster parents and staff; and (6) newspaper advertisements.

Recommendation. An aggressive recruitment program for group home personnel should be launched.

Recommendation. Supplemental payment should be made available to those foster parents and group home personnel who provide training to the children or adults in their care.

Recommendation. Special training programs should be available and manditory for foster home parents and group home personnel. In order to reduce turnover and 'burn out' problems, respite care and other support services should be available to foster home parents and group home personnel.

Recommendation. In keeping with the developmental model and normalization principles, no placement should be considered 'permanent.' All placements and client programming should be aimed toward helping the retarded person move toward ever greater independence and a less restrictive environment.

Recommendation. In keeping with recent legal decisions, residential services should adhere to the principle of 'least restrictive alternative.'

Recommendation. Nursing homes should be used only for those individuals needing nursing care. As soon as possible, individuals so placed should move to a less restrictive environment. Nursing homes should not be used as a substitute for foster homes or group homes.

Recommendation. Those responsible for placement into and from group homes should adhere to laws concerning tenant rights. For example, since an adult group home resident is essentially a tenant paying rent for a place to live, he/she should be afforded a 30-day notice prior to a placement change or a change in the rental agreement. Moreover, persons in community residential services should not be subject to indiscriminate moves or transfers without regard to the individual's desires.

Recommendation. Federal agencies such as H.U.D., the Small Business Administration, etc., should be consulted in an effort to make use of federal funds available for the purchase of group homes.

DIAGNOSTIC AND EVALUATION SERVICES

Recommendation. The initial diagnostic workup must be viewed as a very critical period for parents. Explanations by professionals must be unhurried, simple, thorough and individualized. Technical language should be avoided. Counseling should follow the explanation of findings. Subsequent to the evaluation, follow along services should be provided in order to make sure that the parents really understand the findings and also secure the services needed by their child.

Recommendation. Follow up activities, subsequent to diagnostic and evaluation sessions, should be expanded. Greater emphasis must be placed on early childhood screening, detection and intervention. However, the hazards of premature labeling must be recognized and avoided. A single source of data (e.g., an I.Q. score) should not be used to establish a diagnosis of mental retardation. Rather, a wide variety of data (standardized test data, clinical observation, social history, observation of behavior in natural settings, etc.) must be utilized. For these reasons multidisciplinary teams should be involved in the diagnostic process. For example, diagnostic teams should consist of physicians, speech and hearing specialists, social work specialists, psychologists, learning disabilities specialists, public health nurses, etc.

FOLLOW ALONG AND CASE MANAGEMENT

Recommendation. Notable deficiencies in Montana's current service system for the developmentally disabled are in the areas of follow along, individual program planning and client program coordination. Service

systems in many other states have similar deficiencies. Only a few states (e.g., Nebraska, Connecticut) appear to deal effectively with this complex aspect of service delivery.

Recommendation. As a means of correcting these deficiencies, it is suggested that relevant agencies adhere to principles and guidance offered by the Standards for Community Agencies Services, Persons with Mental Retardation and Other Developmental Disabilities (J.C.A.H., 1973). Portions of the Standards are presented below.

> Definition. The individual program plan is a written plan of intervention and action that is developed, and modified at frequent intervals, with the participation of all concerned. It specifies objectives and goals and identifies a continuum of development, outlining projected progressive steps and the developmental consequences of services.
>
> Principles. An individual program plan should be developed for each person accepted for service, regardless of chronological age or developmental level. The plan should be based on individual assessment data and on other data that assist in understanding the client's situation, and it should be developed by the relevant staff of the agency serving the client, with the participation of the staff of other agencies involved in serving the client, and with the participation of the client and his family. A plan developed prior to the onset of services by the agency should be reviewed and updated, so as to meet the current needs of the client. Long- and short-term objectives should be stated separately and within a time frame, and they must be expressed in behavioral terms that provide measurable indices of progress, and that enable the effectiveness of interventions to be evaluated. Modes of intervention for the achievement of the stated objectives must be specified, and agencies capable of delivering the needed services should be identified. The individual program plan must be modified as goals and objectives are, or are not, attained. Review and appropriate revision of the plan must be a continuous and self-correcting process. The plan must help all concerned to coordinate their efforts and activities, so as to maximize services to the client.
>
> Definition. Follow along means provision for a continuing relationship with the client and his family, which may be life-long, if desired, for the purpose of assuring that changing needs are recognized and appropriately met. The agency also acts as a point

of reference for those who have left a service, but who might seek support or guidance as needs arise.

Principles. Follow along should assure the client of the right to a life-long service, if desired. The service should be designed to assure movement toward long-range goals by a process that monitors placement and that provides appropriate support, counsel, and help.

Definition. Client program coordination is the process by which responsibility for implementation of the client's individual program plan is established. The client program coordinating process includes providing support, procuring direct services, coordinating services, collecting and disseminating data and information, and monitoring the progress of the client.

Principles. Upon acceptance for service by an agency, each client should be assigned a client program coordinator whose duty is to ensure the provision and the effective continuation of necessary services. The client program coordinator should be responsible for the development and implementation of the client's individual program plan, and for assuring that all relevant staff within or without the agency, as well as the client and his family, focus their efforts on attaining the objectives specified in the plan. The client program coordinator's function should be terminated only when responsibility for service to the client has been effectively assumed by another agency, at which time a new client program coordinator should be assigned by the agency assuming responsibility. A client may have more than one client program coordinator if he is receiving services from more than one agency. The ultimate client program coordinator is the family or the client himself.

Recommendation. Those responsible for providing follow along services should have a good understanding of the developmentally disabled, D.D. services, and training in behavior modification and management.

Recommendation. Individual program planning should be made by a transdisciplinary team.

Recommendation. Follow along services and approaches, individual program planning and client program coordination should be so designed and structured to assure the successful community placement of BRS&H residents and the continuation of client training and treatment programs begun at the BRS&H.

INFORMATION AND REFERRAL

Recommendation. An Information and Referral service should be established in each of Montana's five regions. This would provide a fixed point of referral for each region's system of service. Ideally, I & R should be integrated with follow along and case management services and provided within a single agency.

Recommendation. A set of service terminology and definitions should be developed. These definitions should be simply written and understandable to parents. Definitions should be widely distributed among service providers and ARC chapters.

Recommendation. A region-wide directory of services and resources should be prepared and widely distributed to parents and providers of service. Newspapers, public service announcements on radio and TV and other means should be utilized to inform people of available services.

Recommendation. A pool of informed and experienced parents should be available to accept referrals from physicians in order to provide informal counseling and emotional support to parents who have recently given birth to a retarded child or have learned that their child is retarded. It is suggested that ARC chapters establish this community resource.

ECONOMIC ASSISTANCE

Recommendation. The Social Security Office in conjunction with Public Welfare and Public Health personnel should develop and implement an aggressive outreach program for developmentally disabled children and adults who might be eligible for SSI benefits.

Recommendation. A lack of income should not prevent retarded persons from obtaining needed services. Sliding fee schedules or family financial supplements should be implemented. No one should be denied services because of an inability to pay.

Recommendation. In view of the fact that those services funded by Title XX of the Social Security Act require income testing, such procedures should be as simple as possible and conducted in a manner which will minimize the stigma associated with use of the means test in social welfare programs.

RECREATION

Recommendation. Recreational services should be available to all mentally retarded persons needing and wanting such services. However, special programs for the retarded should not be created unless absolutely necessary. In keeping with normalization principles, the mentally retarded should participate in generic programs such as those provided by the YMCA, YWCA, city recreation departments, etc.

Recommendation. Mentally retarded persons and other developmentally disabled persons should be provided with training necessary to facilitate their use of existing community recreation and leisure time activities (e.g., movies, camping, bowling, etc.).

TRANSPORTATION

Recommendation. Individuals should not be prevented from receiving needed services because of a lack of transportation to and from the service

program. Neither should families be forced to move in order to secure services for their child. Transportation services should be available to all those needing it. The development of public transportation in all major communities should be promoted. Developmentally disabled persons should be trained in the use of public transportation. In the absence of public transportation, special transportation for the developmentally disabled will be needed. In keeping with normalization, however, special transportation services should not be created where generic services exist.

MEDICAL AND DENTAL SERVICES

Recommendation. Parent groups such as ARC Chapters or information and referral centers should develop and maintain a list of physicians, dentists and optometrists who have expressed an interest in serving mentally retarded persons and/or have demonstrated special skill in dealing with the mentally retarded patient.

Recommendation. D.D. Service providers and ARC Chapters should make a special effort to develop informational programs and/or written materials which would inform physicians of developments in community based services and counteract the belief that custodial or institutional care is the only alternative for the severely and profoundly retarded.

Recommendation. Various forms of in-service training on interaction and communication with mentally retarded persons should be made available to hospital personnel, physicians and other medically related professionals.

Recommendation. Special training programs should be available to physicians, dentists, nurses and other health care personnel who desire to

acquire special knowledge and skills related to the proper management of patients who are mentally retarded.

Recommendation. Parents and guardians of retarded and other developmentally disabled persons should be encouraged to review their private health insurance policies in order to gain a thorough understanding of coverage and exclusions from coverage.

Recommendation. In order to facilitate the utilization of medically related social service benefits provided by certain private health insurance programs, consideration should be given to the passage of a state licensure law for social workers. (Several insurance companies restrict third party payments to social work practitioners regulated or certified by state law.)

EDUCATIONAL SERVICES

Recommendation. Programs of regular and special education should be available to all children regardless of handicapping conditions. Educational programs should be available to school age youth in BRS&H and those living in the community. (Montana legislation has mandated education for handicapped individuals by 1979.) School bus transportation should also be available to all mentally retarded students needing assistance in getting to and from school. School buses should provide transportation to and from the students' homes (i.e., door to door).

Recommendation. The segregation of the mentally retarded within educational settings should be avoided. To the greatest extent possible, the mentally retarded student should be integrated into regular classes and regular school activities. However, integration does not mean the haphazard "dumping" of retarded persons into regular classes without regard

to the individual's handicap, needs or desires. Neither is it forcing such students into impossible competitions. Integration requires highly qualified teachers who are capable of individualizing educational approaches and of being conscious of the student's readiness, his/her likelihood of success in the educational milieu.

PROTECTIVE SERVICES AND GUARDIANSHIP

Recommendation. Law and administrative procedures relating protective services (e.g., guardianship, conservatorship, trusts, etc.) should be clarified. If such services are needed for an individual, the least restrictive alternative possible should be utilized.

OTHER SUPPORT SERVICES

Recommendation. A wide array and continuum of community based supportive services must be developed in Western Montana. Without such services, deinstitutionalization for the Western Montana citizens now at BRS&H will be impossible.

Recommendation. Greater attention must be given to development of community based programs for the severely and profoundly retarded and the multiply handicapped retarded of all ages. A consortium between general hospital, special education and other community agencies should be explored as a means of developing the developmental maximation units in major Western Montana communities. (See Menolascino and Pearson, Beyond the Limits, 1974)

Recommendation. Speech therapy and language development services, physical therapy, toilet training, behavioral modification, self-help training and similar specialized services should be available to all retarded persons needing these services.

Recommendation. Since corrective measures introduced in early childhood can reduce the severity of the handicap and sometimes reverse its course, a whole range of services should be available to the preschool developmentally disabled child. This should include early diagnosis, infant stimulation, physical therapy, speech therapy, respite care, parental education and training, etc. Wherever possible, such services should be integrated with regular public school programs so as to provide a continuum of training and educational services.

Recommendation. Counseling services should be available to retarded individuals and their parents. To the greatest extent possible, the stigma associated with counseling should be eliminated.

Recommendation. Workshops on counseling with the retarded and the parents of retarded persons should be available to professionals, parents and interested citizens. Better use should be made of persons meeting Wolfensberger's criteria for being a good counselor, regardless of professional affiliation, formal credentials or lack thereof.

Recommendation. Part time or respite care services should be established in major communities throughout the region. Respite care can be provided in or out of the parents' homes. Such programs might take the form of a corporation of trained baby sitters, homemaker service, vacation or weekend care, nursing service, etc. Various types of respite care have been described in Respite Care for the Retarded, by Paige, (1972). One room within each group home can also be utilized for respite care.

COMMUNITY EDUCATION AND INVOLVEMENT

Recommendation. A great variety of techniques and approaches should be used to inform the public about mentally retarded and developmentally disabled persons, their rights and existing services. These might include the public showing of relevant films, program open houses, newspaper features, public speeches and presentations, presentations on TV and radio, etc. Special efforts should be made to reach potential employers of the developmentally disabled and those whose actions and decisions could hamper the development of community group homes such as local zoning authorities.

Recommendation. Regional and State D.D. Councils, Chapters of ARC and others should make special efforts to inform parents, professionals and the public about successful community programs. Personal visits to such programs appear to be the most effective method of public education. Since the public seems to be more impressed by examples "close to home" than examples found in another state or area, special efforts should be made to establish outstanding examples in many parts of the state. These then would serve as demonstrations of successful deinstitutionalization approaches.

Recommendation. If deinstitutionalization is to succeed, federal, state and local governments must demonstrate their continued and long-term support of community based alternatives. One approach is to involve consumers, community professionals, interested citizens, and public officials in the establishment of long-range planning and budgeting for deinstitutionalization. Wide public support for these long-range plans and endorcements by political parties would do much to allay fears.

Recommendation. The SRS Developmental Disabilities Bureau should develop a library of books, films and other educational material which could be made available to providers, parents and organizations. A similar library should be created by the Montana Association for Retarded Citizens.

THE NATIVE OFFENDER

Recommendation. In order to meet the needs of the legal offender who is mentally retarded, specialists in mental retardation, courts and law enforcement personnel must engage in cooperative and coordinated effort. A special task force should be established to study this problem in Montana and formulate plans and programs.

Recommendation. Relevant in-service training programs concerning the needs and behavior of retarded and developmentally disabled persons should be made available to city, county and state law enforcement and correctional personnel.

Recommendation. Each major community should create a pool of mental retardation professionals or other informed and experienced individuals who could be consulted and/or involved in the questioning of a mentally retarded person suspected of or accused of a crime.

MANPOWER DEVELOPMENT

Recommendation. Relevant in-service education and staff development programs on service to developmentally disabled individuals, both children and adults, should be made available to professionals and paraprofessionals working in school, mental health, public health, social service and similar

programs. Both direct services and administrative personnel should participate. It is critical that relevant staff development and in-service training programs are made available to persons working in newly developed programs and to persons who have had little or no experience in service to the developmentally disabled.

Recommendation. Program administrators, staff development personnel, providers and other knowledgeable persons should make a special effort to identify and specify the type of training needed by persons working within the service delivery system. In addition, decisions should be made regarding what "mix" of formal preparation (e.g., university education), on-the-job training and staff development is necessary to generate the various types of skilled manpower needed to provide high quality services for the developmentally disabled.

Recommendation. Given the fact that resources for staff development and in-service training (e.g., personnel, films, books, etc.) are both expensive and in short supply, interagency agreements should be utilized to share and exchange such resources.

ARCHITECTURAL BARRIERS

Recommendation. Schools and all other public buildings should be remodeled so as to permit easy entrance, exit and usability by physically handicapped persons. Special funds must be available to group homes, foster homes, and to natural parents for the construction of ramps and the elimination of architectural barriers such as narrow doorways, inadequate bathrooms, etc. Care should be taken so as to minimize the impact of such modifications

on the aesthetic features of the building. Modifications should conform to the latest edition of American Standard Specifications for Making Buildings and Facilities Accessible to and Usable by The Physically Handicapped, published by the American Standards Association.

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